

MOVING RESEARCH INTO PRACTICE:
THE DIFFUSION OF EVIDENCE-BASED RECOMMENDATIONS
THROUGH PROFESSIONAL SOCIETIES

by
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ABSTRACT

INTRODUCTION

There is a substantial need among clinicians for health-related, evidence-based recommendations. Evidence-based recommendations help distill research findings and aid health care providers in making clinical decisions. However, it is infeasible for providers to sort through thousands of available guidelines, and heterogeneity among recommendation developers (e.g., composition, processes, outputs) can make it difficult for clinicians to identify which recommendations are trustworthy, feasible, and applicable to their patient population. Even when there is broad consensus about the quality and utility of recommendations, a range of contextual factors (e.g., the health care system, patient characteristics, enabling resources) can impede implementation. This study examined the diffusion of evidence-based recommendations through professional societies to clinically-trained members, and explored knowledge, attitudes, beliefs, and behaviors regarding evidence-based recommendations and practice. The study had three aims:

- 1) Describe the role primary care professional societies play in developing and/or disseminating evidence-based reports and recommendations.
- 2) Determine if the needs of primary care providers and their professional societies for evidence-based reports and recommendations are being met.
- 3) Describe the value that the federal government contributes to evidence-based practice.

METHODS

To achieve these aims, content analysis was used to examine transcripts from 34 semi-structured telephone interviews of leaders and members from eight health-related professional societies. Nonprobability, purposive sampling of knowledgeable experts enabled in-depth exploration of phenomena. An interview guide was developed using theory-driven concepts and theoretical frameworks, and was pilot tested using cognitive interviewing techniques. The codebook

included theory-and data-driven codes and was revised through an iterative process that included intercoder reliability assessments.

RESULTS

There were differing views on the meaning of “evidence-based”, but there was broad agreement on its scientific underpinning and the importance of conducting “evidence-based practice.”

Professional societies can play several roles (i.e., disseminator, liaison, developer, and/or facilitator) in the promotion of evidence-based recommendations and practice. Views varied on whether the needs of primary care providers and their professional societies for evidence-based reports and recommendations were being met. Federally-sponsored recommendation developers were viewed as valuable contributors to evidence-based practice because of their objectivity, transparency, balance, methodological rigor, and prioritization. Study participants offered many suggestions for improving the development, feasibility, readability, acceptability, and dissemination of evidence-based recommendations. Participants also offered input on how federally-sponsored recommendation developers could strengthen their partnerships with stakeholders, including professional societies and their members.

CONCLUSION

The issue of trust was central to participants’ attitudes and beliefs; therefore, recommendation developers should integrate transparency and three factors that bolster trust (ability, benevolence, and integrity) into their processes. Federally-sponsored recommendation developers should consider collaborating with professional societies in a variety of ways to develop and disseminate recommendations to facilitate evidence-based practice. The federal government can also promote the use of evidence-based recommendations by improving its guideline clearinghouse, expanding health insurance coverage to more Americans, requiring that recommendations be covered by insurance, and supporting research on point-of-care decision support tools, electronic health records, and workflow training for health providers.

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DEDICATION

This work is dedicated to my mother, Susie, whose loving memory inspired this journey and to my son, Sam, whose joyful laughter supported its completion.

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TABLE OF CONTENTS

ABSTRACT	ii
DEDICATION	v
ACKNOWLEDGMENTS	vi
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: LITERATURE REVIEW	7
2.1 Overview	7
2.2 NIH Office of Disease Prevention (ODP) and Evaluation of an ODP Program	7
2.3 NIH Consensus Development Program (CDP)	8
Impetus for Creating the CDP	8
Principles and Mechanics of the CDP	9
CDP Outcomes	11
Critiques of the CDP	12
2.4 Colorectal Cancer Screening	14
Disease Burden	14
Natural History and Risk Factors	15
Screening Methods and Trends	16
Colorectal Cancer Screening Issues	18
Heterogeneity in Screening Recommendations	19
2.5 Health-Related Reports, Recommendations, and Scientific Panels	24
Need for Synthesized Research Evidence Reports and Health-Related Recommendations	24
Types of Reports, Recommendations, and Other Resources	24
Sponsoring Organizations, Their Scientific Panels, and Recommendations.....	26
Issues Regarding Recommendations	28

2.6	Professional Practice and Control	31
	Professions	32
	Professional Control and Tensions	33
	Determinants of Provider Practice	34
	Practice Change	38
	Professional Societies	41
2.7	Diffusion of Innovations	43
	Diffusion and Dissemination	43
	Diffusion Elements	44
	Adopter Categorization	45
	Innovation-Development Process	46
	Innovation-Decision Process	47
	Innovation in Organizations	48
2.8	Study Goal, Specific Aims, and Research Questions	49
CHAPTER 3: METHODS		51
3.1	Overview	51
3.2	Study Population	51
3.3	Sampling	52
3.4	Recruitment	53
3.5	Qualitative Approach	54
3.6	Data Collection and Analysis	55
	Data Collection	55
	Data Analysis	56
3.7	Human Subjects Considerations	58
CHAPTER 4: RESULTS		60
4.1	Overview	60

4.2	Study Participant Characteristics	60
4.3	Professional Society Characteristics and Innovation	61
4.4	Views on Evidence-Based Recommendations and Practice	65
4.5	Professional Society Support of Evidence-Based Recommendations and Practice	70
4.6	Awareness, Knowledge, Attitudes, and Beliefs about Organizations and Their Scientific Panels	73
4.7	Provider Utilization of Scientific Panel Reports and Recommendations	90
4.8	Value Federal Government Contributes to Evidence-Based Practice	97
4.9	Comments and Suggestions for Federal Scientific Panels	99
	Improving Panel Composition and Processes	99
	Making Recommendations More Feasible to Implement	101
	Improving Readability, Acceptability, and Dissemination	102
	Strengthening Partnerships with Stakeholders	105
4.10	Summary of Main Findings	108
CHAPTER 5: DISCUSSION		111
APPENDICES		123
REFERENCES		188
CURRICULUM VITAE		201

LIST OF TABLES

Table 1: Patient, Provider, and System Level Factors that Contribute to Low Colorectal Cancer Screening Rates	18
Table 2: Colorectal Cancer Screening Recommendations from the U.S. Preventive Services Task Force and the American Cancer Society-U.S. Multisociety Task Force-American College of Radiology	21
Table 3: Heterogeneity of Panel Composition and Processes	23
Table 4: NCG-Listed Panels/Groups Included in the Study	27
Table 5: Health Care Professional Societies Involved in this Study	52
Table 6: Sampling for Each Professional Society in this Study	54
Table 7: Demographic Characteristics of Study Participants	61
Table 8: Awareness and Knowledge of the NIH Consensus Development Program	75

LIST OF FIGURES

Figure 1: Foundation of the NIH Consensus Development Program Processes	9
Figure 2: U.S. Colorectal Cancer Incidence and Mortality Rates	15
Figure 3: Evidence Pyramid for the NIH Consensus Development Program	26
Figure 4: U.S. Behavioral Model for Healthcare Utilization	35
Figure 5: Adopter Categorization on the Basis of Innovativeness	45
Figure 6: Cumulative Number of Adopters in the Diffusion Process.....	46
Figure 7: A Model of the Five Stages in the Innovation-Decision Process	47
Figure 8: Five Stages in the Innovation Process in Organizations	48
Figure 9: Independent Variables Related to Organizational Innovativeness	49

CHAPTER 1: INTRODUCTION

The lead investigator for this study is an employee of the National Institutes of Health (NIH), Office of Disease Prevention (ODP) and a doctoral candidate at the Johns Hopkins School of Public Health. This study was initiated to: 1) provide a formative evaluation of an ODP program and 2) contribute original research to the social and behavioral sciences. This dissertation couples both efforts in order to promote a broad understanding of the diffusion of evidence-based recommendations and describes a federal program that sponsors the development of recommendations as well as the perspective of stakeholders that accept or reject those recommendations.

Formative Evaluation for the NIH Office of Disease Prevention

The formative evaluation was intended to provide the ODP with information to assist decision-making and improve the design and outcomes of its Consensus Development Program (CDP). The CDP convened scientific panels to produce unbiased, evidence-based assessments of controversial and complex medical issues and offered evidence-based recommendations to advance research and clinical practice. The CDP assembled 159 panels from 1977-2013 and disseminated panel assessments and recommendations to a variety of stakeholders (e.g., researchers, health care providers, policymakers, patients).

Many at NIH voiced support for the CDP, but by 2010, senior NIH leadership was questioning the program's methods and utility. In response, the ODP began a formative evaluation focused on the CDP's structure, methods, and dissemination of recommendations to a key stakeholder constituency (i.e., primary care providers and the professional societies that represent them). The study was designed to explore many issues, including:

- Panel composition and processes
- The dissemination of CDP evidence-based recommendations

- The usefulness of CDP recommendations in promoting evidence-based care
- Suggestions for improving the CDP, enabling it to provide more trustworthy, pertinent, and feasible recommendations for its stakeholders.

Despite efforts to evaluate and improve the program, the CDP was retired in 2013 following an office reorganization. In its place, the ODP created a new, but similar program, Pathways to Prevention (P2P). The P2P program also convenes scientific panels, but these panels primarily make research, not clinical, recommendations. Additionally, the P2P program was built to accommodate cost-saving measures and have more timely processes than the CDP.

The retirement of the CDP did not end the program evaluation; rather, it served to broaden its scope. To gain a better understanding of how scientific panels can be effective in developing and disseminating evidence-based recommendations, research questions were expanded to collect information about other panels supported by federal agencies, nonprofit organizations, disease specific societies, and medical specialty societies. While the findings of this study identify the CDP's strengths and weaknesses, it also notes these characteristics in other panels as well, providing the ODP with insights for enhancing P2P and other programs and initiatives. Furthermore, the evaluation offers guidance for improving other federally-sponsored panels (e.g., U.S. Preventive Services Task Force, Community Preventive Services Task Force), which are ODP partners.

Contributing Original Research to the Social and Behavioral Sciences

This study contributes original research to the social and behavioral sciences by applying well-known theories and theoretical frameworks to examine phenomena from the perspective of professional society leaders and members. Everett M. Rogers' (2003) Diffusion of Innovations is used to examine professional society characteristics, activities, perceived innovativeness, and promotion of evidence-based assessments and recommendations. Ronald Andersen's (1995) Behavioral Model for Healthcare Utilization is used to examine contextual variables that can

influence the implementation of evidence-based recommendations. Eliot Freidson's (1984) work on professional practice and control is used to analyze tensions between those that develop recommendations and those asked to carry them out. The study explores individual and social environmental factors that impact the translation of research into practice.

The Need for Evidence-Based Recommendations and Obstacles to Their Implementation

This study examined the diffusion of evidence-based recommendations—through professional societies to their clinically-trained members—in order to promote quality, evidence-based practice. There is a substantial need among clinicians for health-related, evidence-based recommendations. There are thousands of randomized controlled trials (RCTs) published annually, and evidence-based recommendations help distill research findings and aid health care providers in making clinical decisions (IOM, 2011). However, it is infeasible for providers to sort through the approximately 6,500 published guidelines (GIN, 2013), that have been developed by a variety of scientific panels from over 200 organizations (NIH-CDP, 2010b). Moreover, heterogeneity in panel composition, processes, and outputs can make it difficult for clinicians to identify which recommendations are trustworthy, feasible, and applicable to their patient population. Even when there is broad consensus about the quality and utility of recommendations, a range of contextual factors (e.g., the health care system, patient characteristics, enabling resources) can impede implementation (Andersen, 1995). With so many obstacles hindering the translation of quality research into clinical practice, the lag time between scientific discovery and when most Americans benefit from research findings has been estimated to be 17 years (Clancy, 2006).

Using the Topic of Colorectal Cancer Screening to Anchor the Study

Examining the diffusion of evidence-based recommendations can become unwieldy with thousands of guidelines available for consideration. The lead investigator chose to use one topic,

colorectal cancer screening, to anchor the study and serve as a starting point for discussion with study participants. Focusing on this topic was useful for the following reasons:

- 1) Colorectal cancer (CRC) screening was the focus of a 2010 CDP panel, which provided recommendations on the topic.
- 2) The Institute of Medicine (2011) highlighted CRC in a report because of the heterogeneity in screening recommendations provided by a variety of scientific panels.
- 3) CRC is of broad public health importance and the implementation of screening guidelines has been shown to save lives (AHRQ, 2010). However, researchers at the National Cancer Institute found that only 19.1% of physicians made “guideline-consistent recommendations across all CRC screening modalities” (Yabroff et al., 2010).

The topic of CRC screening exemplifies complexities surrounding the development of evidence-based recommendations and permits examination of how life-saving innovations (CRC screening modalities, packaged in recommendations to direct use) are accepted or rejected by professional societies, disseminated to membership, and utilized by clinicians. Although CRC screening served as a starting point for discussion, it often led to comments about other topics (e.g., breast cancer screening, prostate cancer screening, cholesterol screening) tackled by both federal and non-governmental panels.

Study Aims and Methods

The overall goal of this study was to identify the role of scientific, federally-sponsored panels in promoting evidence-based practice and determine how these panels can better meet the needs of primary care providers and their professional societies for evidence-based reports and recommendations. The study aimed to:

- 1) Describe the role primary care professional societies play in developing and/or disseminating evidence-based reports and recommendations.

- 2) Determine if the needs of primary care providers and their professional societies for evidence-based reports and recommendations are being met.
- 3) Describe the value that the federal government contributes to evidence-based practice.

To achieve these aims, content analysis was used to examine 34 semi-structured interviews of leaders and members from eight health-related professional societies.

Study Findings Related to Aims and Dissertation Structure

This study found that professional societies play a variety of roles in promoting evidence-based practice, including those of information disseminator, partnership liaison, direct developer of recommendations or measures, and facilitators of evidence-based programs and initiatives. Professional societies aim to change health provider practice through a variety of mechanisms (e.g., journal articles, official guidelines, conferences, strategic programs and initiatives) and the federal government could work more closely with these organizations to leverage resources and promote evidence-based practice.

Scientific panels sponsored by federal agencies and non-governmental organizations are meeting some of the need for evidence-based reports and recommendations. However, there are gaps in the topics covered, confusing heterogeneity among recommendations, many poor quality recommendations, and a lack of transparency that inhibits a clinician's ability to directly and accurately evaluate and compare recommendations. The federal government can address these issues by bolstering national clearinghouse criteria for guidelines, identifying research gaps, funding new applicable research, and partnering with others to harmonize recommendations.

Federally-sponsored scientific panels are valuable contributors to evidence-based practice, bringing objectivity, transparency, balance, methodological rigor, and effective prioritization to the development of evidence-based reports and recommendations. Moreover, the federal government covers the costs for implementing certain recommendations through the Affordable Care Act.

This dissertation comprises five chapters. Following the introduction, Chapter 2 provides information about the NIH Office of Disease Prevention and the Consensus Development Program; colorectal cancer and its screening; health-related reports, recommendations, and the scientific panels that create them; health professions; and Rogers' (2003) Diffusion of Innovations. Chapter 3 provides a description of study methods, including study population, sampling, recruitment for semi-structured interviews, guiding qualitative approaches, data collection and analysis, and human subjects considerations. Chapter 4 reports the study's results, with illustrative quotes from interviewees. Chapter 5 discusses the study's findings, limitations, and implications for the federal government and public health.

CHAPTER 2: LITERATURE REVIEW

2.1 Overview

This chapter begins with a review of the NIH Office of Disease Prevention and its Consensus Development Program (CDP), including the creation, guiding principles, outcomes, critiques, and retirement of the CDP. This is followed by an examination of colorectal cancer screening, an important public health topic the CDP assessed in 2010, which also elucidates the complexities of diffusing evidence-based recommendations (e.g., quality and heterogeneity of scientific panels and their recommendations, contextual factors which impede the implementation of evidence-based strategies). The next section addresses the need for trustworthy panel processes and outputs and proposed standards for developing them. This is followed by a review of health professions (i.e., their control, determinants of provider practice, practice change, and tension among professionals) and the functions professional societies serve—including translating evidence into practice. The chapter concludes with a review of Everett M. Rogers' theoretical framework, Diffusion of Innovations, and the specific aims and research questions of this study.

2.2 NIH Office of Disease Prevention (ODP) and Evaluation of an ODP Program

The ODP was created in 1986 to promote and coordinate disease prevention and nutrition research activities and to conduct evidence-based assessments of the state of the science and medical practice. (ODP, 2014). To help fulfill this mission, the ODP inherited the NIH Consensus Development Program, which was intended to produce unbiased, evidence-based reports of controversial or complex medical issues to advance understanding among health professionals and the public (NIH-CDP, 2011a).

Beginning in late -2010, the ODP sought a formative evaluation of the CDP to identify ways to improve the program. Although the CDP was retired in 2013, findings from this study not only

provide an understanding of the CDP's strengths and weaknesses, but they also provide the ODP with valuable insights for enhancing other programs and initiatives.

The ODP, which has been reorganized several times (most recently in 2012), released a strategic plan in 2014 which centered on efforts intended to:

- Extend the value of ODP as a resource to the NIH and broader prevention research community
- Provide guidance in prevention research methodology
- Identify gaps in existing evidence
- Facilitate coordination of new activities to address those gaps
- Promote quality improvements in the review of prevention research
- Increase the impact and visibility of prevention research. (ODP, 2014c).

The results of this study support several of the efforts listed above and directly assist the ODP in achieving a key strategic priority:

Identify and promote the use of evidence-based interventions and promote the conduct of implementation and dissemination research in prevention. (ODP, 2014d)

2.3 NIH Consensus Development Program

Impetus for Creating the CDP

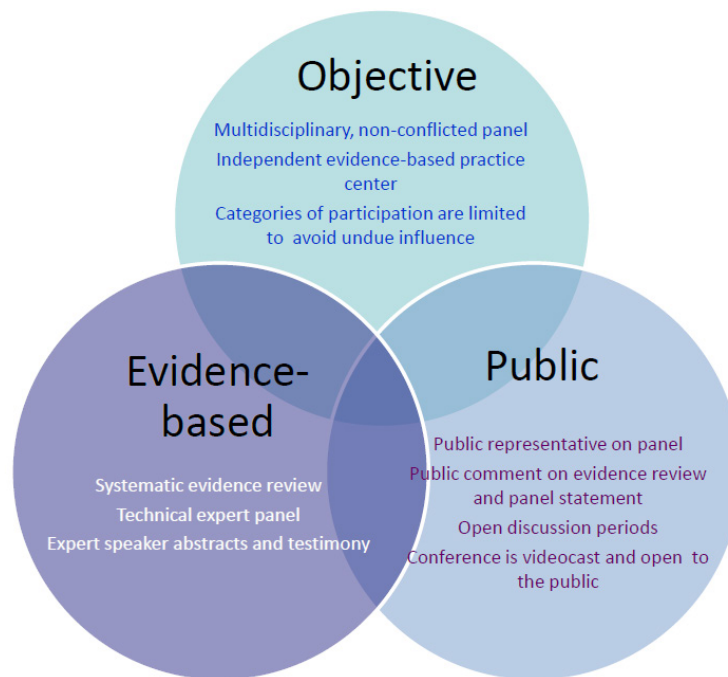
In the 1970's, there was substantial public pressure to increase medical accountability due to rising health care expenditures and the perception that "these increases were at least partly due to the premature application of expensive technical innovations in medicine before their safety, efficacy, and costs had been adequately evaluated" (Perry, 1987, p. 485). In 1976, the Congressional Office of Technology Assessment concluded that reviews of medical innovations would be useful in decision-making, and Senators Jacob Javits (R-N.Y.) and Edward Kennedy (D-Mass.) urged NIH to play a prominent role in assessing the effectiveness, benefits, risks, and

societal impacts of medical technologies (Perry & Kalberer, 1980; Wortman et al, 1988). In response, the NIH created the CDP in 1977.

Principles and Mechanics of the CDP

The CDP sought to improve the translation of biomedical research into knowledge that could be used effectively in the practice of medicine and public health (Lowe, 1980). To achieve its aim, CDP processes were designed to be objective, evidence-based, and involve the public. (NIH-CDP, 2010c). See Figure 1.

Figure 1: Foundation of NIH Consensus Development Program Processes. (NIH-CDP, 2010c)



Topic proposals were developed by NIH scientists—sometimes in collaboration with other federal partners, such as the Centers for Disease Control and Prevention—in response to research gaps or the failure of strong evidence to be widely translated into clinical practice (NIH-CDP, 2012b). Topic proposals were submitted to the ODP for initial consideration and later reviewed at an organizational meeting with staff from relevant NIH Institutes and Centers and other federal agencies. Accepted topics were required to meet the following criteria:

- Have clinical and broad public health importance - the severity of the problem and the feasibility of interventions were key considerations
- Be controversial or unresolved and amenable to clarification, or reflect a knowledge and practice gap that could be narrowed
- Have an adequately defined base of scientific information from which to answer topic questions. (NIH-CDP, 2012b)

Once a topic was accepted at an organizational meeting, a planning committee of federal and non-federal experts would be convened to: 1) finalize key questions to be addressed, 2) set a date and agenda for a CDP conference, 3) nominate conference speakers, and 4) nominate panelists to weigh the evidence and develop a consensus statement (NIH-CDP, 2010c).

After the planning committee meeting, a systematic evidence review would be performed by one of the Agency for Healthcare Research and Quality's Evidence-based Practice Centers. The resulting evidence report would be examined by an independent panel, which had been carefully screened to ensure members had no financial or intellectual conflicts (NIH-CDP, 2011b).

Six to eight weeks after the panel received the evidence report, a two-and-a-half day conference would be held, consisting of expert presentations and town hall forums to facilitate open discussion among panelists, speakers, and the general public. Lowe (1980) argued that these conferences differed from standard scientific state-of-the-art meetings in that CDP panels had to consider specific sets of questions and issue recommendations framed around those questions.

CDP conferences were likened to a "judicial process or 'science court' procedure"; the conference questions constituted the charge, the evidence report, speakers' presentations, and audience comments provided the evidence, and the panel served as a jury to weigh the evidence and reach a verdict (Wortman et al, 1988, p. 471). The verdict, in the form of a consensus statement, was presented on the third day of the conference for audience commentary. Federal officials were not directly involved in the deliberations of the panel, as NIH staff served only as support for the consensus process (Lowe, 1980). A final report would be released six weeks after

the conference and disseminated to a variety of stakeholders, including professional societies and their members.

By its retirement in 2013, the CDP had sponsored 159 conferences. The CDP held two types of conferences: State-of-the-Science Conferences and Consensus Development Conferences. Both had the same structure and methodology; they differed only in the strength of the evidence surrounding the topic in question (NIH-CDP, 2010d).

When it appears that there is very good evidence about a particular medical topic, but that the information has not been taken up into widespread clinical practice, a Consensus Development Conference is typically chosen, in order to consolidate, solidify, and broadly disseminate a strong evidence-based recommendation for general practice. Conversely, when a medical issue has weak or contradictory evidence, or practice habits not based in high-quality evidence are widespread, a State-of-the-Science Conference is chosen in order to highlight what evidence about a topic is available, the directions future research should take, and to alert physicians that certain practices do not have good data to support them. (NIH-CDP, 2010d, p. 1)

CDP Outcomes

Portnoy et al. (2007) found that CDP conferences appeared to stimulate new, relevant research activities, including NIH-issued initiatives (e.g., requests for applications, program announcements, notices) and investigator-initiated grants. However, the influence of CDP conferences on health providers appeared to be mixed. For example, after a conference on computed tomography scans of the brain, “only about one third of neurosurgeons or neurologists knew of the conference and less than half of these were aware of the conclusions” (Perry, 1987, p. 487). In contrast, conferences on burn care and liver transplantation appear to have influenced provider practice and Medicare coverage policies (Burke, 1981; Perry, 1987). Kosecoff et al (1990) found that the CDP achieved “moderate success in making itself known to physicians” (p.

821), but that conferences mostly failed to stimulate changes in clinical practice (Kosecoff et al, 1987).

Critiques of the CDP

Lowe (1980) pointed out that NIH Consensus Statements, which were authored by independent panelists, were not regulations; they simply represented “the best current thinking by those in the best position to know” (p. 1584). However, since program inception, some medical groups voiced concern that panel recommendations might become regulations, which could turn physicians into “automatons” whose actions were dictated by a small group (Perry, 1987).

The lure of consensus is powerful. Once a consensus is defined—correctly or otherwise—there will be those in academia, in public health, in the insurance fields, in health maintenance organizations, and most surely and most terribly in the fields of law and government who will desire and will move to require strict conformity of practice to the presumed ideal... We must protect the individual choices of each physician from the potential tyrannical domination of consensus. (May, 1985, p. 1077)

The Director of the American College of Surgeons questioned whether CDP conferences should be boycotted (Hanlon, 1980) and one medical professional society threatened to sue the NIH and its panelists (Perry, 1987).

An NIH-funded evaluation of the CDP in the 1980s found that the program was “arguably the most visible and influential medical technology assessment activity in the United States” (Wortman et al, 1988, p. 495); however, there were flaws that undermined its credibility, including:

- The potential for selection bias - particularly with respect to the choice of questions, which “generally reflect the substantive concern of the institute staff responsible for the conference” (p. 476), and panelists, who in the “absence of a systematic, formal procedure...are often suggested and selected by NIH staff (including planning committee members) on the basis of personal acquaintance and professional reputation” (p. 477).

- Insufficient time during conferences to adequately review the evidence, manage disagreements, and draft consensus statements.

Ferguson & Sherman (2001) echoed concerns over time constraints. They surveyed panelists from 69 conferences and noted substantial criticism of the short window of time to draft the statement, which required late evenings of writing after long days of conference presentations.

Kosecoff et al (1987) argued that CDP conferences were an important education tool. However, it was also noted that better selection of topic questions might have increased the relevancy and effectiveness of conferences and that follow-up programs should have been encouraged for the purpose of dissemination and implementation (Kosecoff et al., 1987 & 1990).

When the ODP was reorganized in 2012, NIH leadership voiced concern that the CDP was expensive, lacked nimbleness, and was duplicative since other organizations were conducting evidence-based assessments. In 2013, the NIH retired the CDP, noting:

The CDP was created during a time when few other organizations were providing evidence reviews. Today, there are many other organizations that conduct such reviews, including other federal agencies, academic institutions, and private organizations. Examples include the U.S. Preventive Services Task Force, the Community Preventive Services Task Force, the Institute of Medicine, and The Cochrane Collaboration. The CDP has served a very useful role, but one that is now served by other able parties. (NIH-CDP, 2013)

In place of the CDP, the ODP has developed a new program to conduct evidence-based assessments of complex public health issues. The Pathways to Prevention (P2P) program convenes workshops similar to the ODP's former State-of-the-Science Conferences in that both were designed to address topics having weak or contradictory evidence. The P2P program is focused on identifying research gaps in a selected scientific area, identifying methodological and scientific weaknesses in that area, and suggesting research needs to move the field forward (NIH-P2P, 2014). P2P Workshops are less expensive and have a more timely process than State-of-the-

Science Conferences, and they focus on research gaps not being addressed by other scientific panels. This study, while helping to evaluate the CDP, will also provide the ODP with stakeholder input for strengthening the P2P program.

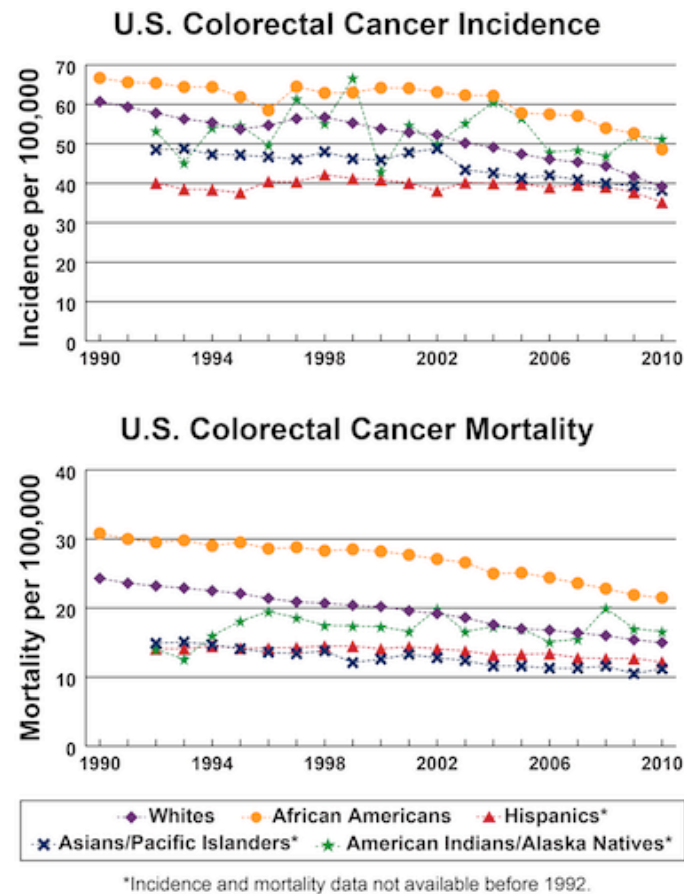
2.4 Colorectal Cancer Screening

Evidence-based recommendations have been developed for numerous topics. To elucidate important issues in developing and implementing recommendations, this study focused on colorectal cancer screening. This topic was the focus of a 2010 CDP conference (NIH-CDP, 2010a) and was highlighted by the Institute of Medicine in 2011 for its complexity and heterogeneity of recommendations (IOM, 2011). Colorectal cancer screening served as a starting point for discussion, and often led to insightful comments about other screening recommendations in primary care practice. Background information on colorectal cancer screening is provided below.

Disease Burden

Colorectal cancer (CRC) is the third most common nonskin cancer and the third highest cause of cancer death among men and women in the United States (NCI, 2011). There were an estimated 142,820 new cases and 50,830 deaths in 2013 (NCI, 2014). Before age 50, men and women have similar incidence and mortality rates; however rates are higher in men after the age of 50 (NCI, 2011). Non-Hispanic blacks have the highest incidence and mortality rates of any racial or ethnic group and are more likely to develop colorectal cancer at an earlier age (IOM, 2008). See Figure 2.

Figure 2: U.S. Colorectal Cancer Incidence and Mortality Rates. (NCI, 2013)



Source: Surveillance, Epidemiology, and End Results (SEER) Program and the National Center for Health Statistics. Additional statistics and charts are available at the SEER Web site.

In addition to the burden of illness and tragedy of lives lost, there are tremendous economic costs related to the disease; approximately \$14.1 billion is spent annually for CRC medical expenditures (NCI, 2013).

Natural History and Risk Factors

Colorectal cancers begin as benign adenomatous polyps (Winawer, 1999), or adenomas, and typically progress 5 to 15 years before becoming invasive adenocarcinomas (Rozen et. al., 2002).

This slow progression of disease permits clinicians to identify and remove adenomas before they develop into invasive cancers (IOM, 2008).

Both hereditary and environmental factors play important roles in the development of CRC (Fearon and Vogelstein, 1990). Between 25% and 30% of people with CRC have hereditary factors that put them at increased risk for this disease (Fearon and Vogelstein, 1990; Winawer, 1999).

The increased risk is related to inflammatory bowel disease in 1%, to familial adenomatous polyposis in 1%, and hereditary nonpolyposis colorectal cancer (HNPCC) in 5%. The remaining 15%-20% of high risk individuals have a family history of colorectal cancer in close relatives without an identified genetic predisposition. (Winawer, 1999, p. 4S)

The risk of CRC increases with age; there is a progressive rise from age 40 and a sharp increase after age 50 (Haggard & Boushey, 2009). Modifiable factors, such as diet, physical activity, obesity, smoking and alcohol intake, have also been associated with the development of colorectal cancer (Watson & Collins, 2011). Diets high in animal fat and meat are a major risk factor for disease (Boyle and Langman, 2000; Larsson & Wolk, 2006; Santarelli et al., 2008). Two “interrelated risk factors, physical inactivity and excess body weight, are reported to account for about a fourth to a third of colorectal cancers” (Haggard & Boushey, 2009, p. 195). Cigarette smoking is linked to the development of adenomas (Botteri et al. 2008) and it is estimated that 12% of CRC deaths are attributed to smoking (Zisman et al., 2006). Lastly, heavy drinking, defined as 4 or more drinks a day, has been found to increase CRC risk by 52% (Pelucchi et al., 2011).

Screening Methods & Trends

Death rates for CRC have fallen since the mid-1980s for both men and women (Edwards et al., 2010) and the decline accelerated in the last decade (annual decline between 2002-2005 was 4.3%) (AHRQ, 2010a). Reductions in mortality are widely believed attributable to increased

screening for the disease (Hanley, 2011; Pignone et al., 2002). There is substantial evidence that cancers diagnosed in average-risk asymptomatic individuals through screening are found at a more favorable stage and have lower mortality than cancers diagnosed in unscreened controls (Kronberg et al., 1996). In general, there has been an upward trend in CRC screening rates among adults age 50 and older; for example, screening rates which were 20% to 30% in 1997, increased to nearly 55% by 2008 (Kahi et al., 2009). There are several screening tests for CRC, including the guaiac-based fecal occult blood test (gFOBT), fecal immunochemical test (FIT), flexible sigmoidoscopy (FS), and colonoscopy (NIH-CDP, 2010a). The use of two other screening methods, digital rectal examination and double contrast barium enema (DCBE), has precipitously declined in recent years, and two newer tests, fecal DNA and computed tomographic colonography (CTC), are not in widespread use (Cardarelli & Thomas, 2009). Fecal DNA screening may increase since the FDA's Medical Devices Advisory Committee unanimously approved the use of a multi-target stool DNA screening test in March 2014 (Bin Han Ong, 2014). Screening tests can be divided into two categories: 1) tests that primarily detect CRC (gFOBT, FIT, fecal DNA) and 2) those that detect both CRC and precancerous colonic polyps (FS, colonoscopy, CTC, barium enema) (AHRQ, 2010a).

Despite a range of screening methods, only gFOBT has been tested in full randomized controlled trials (RCTs) of CRC screening (AHRQ, 2010a). In the last 20 years, four RCTs of screening with gFOBT found a "relative reduction of 16 percent to 33 percent in CRC mortality (absolute risk reduction = 2.9 deaths/1,000 over 13 years in the U.S. trial), first appearing 5 to 7 years after start of screening" (AHRQ, 2010a, 11). A good quality case-control study in the mid-1990s bolstered the case for FS (Coughlin & Thompson, 2005). Some studies have indicated colonoscopy reduces CRC death rates (Kahi et al., 2009); however, the recommendation for colonoscopy has been largely based on extrapolated benefits from studies of FOBT and FS (AHRQ, 2010a).

Colorectal Cancer Screening Issues

Three issues have been cited that compromise the beneficial impact of CRC screening: underuse, overuse, and misuse.

1) Underuse of Screening - Scientific panels have recognized the importance of CRC screening for asymptomatic average-risk adults, and the value of screening has also been “prioritized by the National Commission on Prevention Priorities as an important service with high public health value” (NIH-CDP, 2010b, p. 31). However, underuse of CRC screening among adults age 50-75 is a serious public health issue (NIH-CDP, 2010b). Although screening rates for CRC have increased in the last ten years for most population subgroups, disparities in screening exist. Colorectal cancer screening rates are “significantly lower among minority, low SES [socioeconomic status], and rural populations” (NIH-CDP, 2010b, p.41). Moreover, screening rates have not significantly increased for individuals with no usual source of care, no physician visits in the past year, or who lack health insurance (NIH-CDP, 2010b). A number of factors contribute to low CRC screening rates; see Table 1 for a listing of factors cited in the literature (NIH-CDP, 2010b; Zapka, 2008; Klabunde et al., 2005).

Table 1: Patient, Provider, and System Level Factors that Contribute to Low Colorectal Cancer Screening Rates. (NIH-CDP, 2010b; Zapka, 2008; Klabunde et al., 2005)

Patient Level Factors	Provider Level Factors	System Level Factors
Lack of provider recommendation for screening	Lack of knowledge or disagreement with guidelines	Lack of reminder and tracking systems
Lack of awareness and knowledge	Concern over efficacy of the screening tests	Lack of patient education and support
Cultural attitudes, beliefs, and norms	Forgetfulness	
Lack of insurance	Lack of time	
Embarrassment	Norms	
Inconvenience	Reluctance to order screening due to cost	
Lack of time	Perceptions of patient compliance	
Fear of cancer	Competing medical priorities	
Perceived discomfort or pain associated with the test		

2) Overuse of Screening - Overuse of CRC screening occurs when:

- There is a preferential use of one test, such as colonoscopy, when less risky (e.g., fewer colonic perforations) and more convenient procedures are available, such as FOBT or sigmoidoscopy plus FOBT
- Screening is used for older persons who are likely to receive insufficient benefit compared to potential harms (e.g., perforations, bleeding)
- Surveillance colonoscopy (after removal of polyps) is conducted more frequently than guidelines suggest—resulting in greater potential harm than benefit (NIH-CDP, 2010b).

3) Misuse of Screening – Misuse refers to screening that is of low quality (e.g., colonoscopy that is poorly conducted or in-office FOBT—a test which should be conducted with three samples collected at home). Dreyfuss wrote that “in-office FOBT [of a sample collected during a digital rectal examination (DRE)] misses 95% of cases of advanced neoplasia, giving patients a false sense of reassurance” (Dreyfuss, 2005, p. 275).

Reducing underuse, overuse, and misuse are critically important to improving CRC screening outcomes, and some argue that appropriate screening recommendations are an important first step in improving screening practices. Ransohoff (2010) stated that because “practice guidelines provide a kind of starting place or ‘set point’ often used to judge overuse, underuse, or misuse, consideration of the quality of guidelines themselves is required” (NIH-CDP, 2010b, p. 45).

Heterogeneity in Screening Recommendations

The availability of evidence-based reports and recommendations is critical to health care providers and patients who face a range of screening options. However, the heterogeneity, quality, and trustworthiness of recommendations have been questioned (Shaneyfelt T.M. & Centor, 2009; Hirsh & Guyatt, 2009).

Of concern is the more than 200 recommendation-developing organizations, covering a range of medical conditions (NIH-CDP, 2010b), with substantial differences in their processes and recommendations.

Guidelines may differ not only in their recommendations but also in the process used to generate recommendations. Differences in process may occur in the composition of the groups of persons who assess evidence and make guidelines; in the process by which the evidence is weighed; and in the fundamental principles or goals that direct the guideline-making process, for example, regarding whether patient outcome is the main focus.

While guidelines ideally might be intended to “do what is best for the patient”, recent commentary has pointed out that that ideal may be compromised by conflicting interests of physicians or professional groups who participate in making guidelines (who may want to maximize economic outcome or professional activity) or from payer or governmental participation (who want to minimize economic costs). Because guidelines play such an important strategic role in practice and in overall quality of care, it is necessary to understand and manage the process of guideline making itself. (NIH-CDP, 2010b, p. 45)

A search in January 2012 using a free, online database of clinical practice guidelines—the National Guideline Clearinghouse (NGC) funded by AHRQ—with the term “colorectal cancer screening”, yielded 19 results from 17 organizations. See Appendix 1. Differences in CRC screening recommendations were highlighted at a 2010 CDP conference, where it was noted that recommendations varied regarding target age group for screening and type of screening test. Table 2 highlights the differences between two sets of recommendations that were discussed at the conference (1. United States Preventive Services Task Force [USPSTF] and 2. American Cancer Society—U.S. Multi-Society Task Force—American College of Radiology [ACS-MSTF-ACR]).

Table 2: Colorectal Cancer Screening Recommendations from the U.S. Preventive Services Task Force and the American Cancer Society-U.S. Multisociety Task Force-American College of Radiology. (NIH-CDP, 2010a)

Screening Test	Description	USPSTF	ACS-MSTF-ACR
Fecal occult blood test (FOBT)* and fecal immunochemical test (FIT)*	Examination of the stool for traces of blood not visible to the naked eye	Recommends high-sensitivity FOBT and FIT annually for ages 50-75	Recommends high-sensitivity FOBT and FIT annually for ages ≥ 50
Sigmoidoscopy*	Internal examination of the lower part of the large intestine	Recommends every 5 years with high-sensitivity FOBT every 3 years for ages 50-75	Age ≥ 50 , every 5 years
Double-contrast barium enema*	X-ray examination of the colon	--	Age ≥ 50 , every 5 years
Colonoscopy	Internal examination of the entire large intestine	Recommends every 10 years for ages 50-75	Age ≥ 50 , every 10 years
Computed tomography colonography*	Examination of the colon and rectum using pictures obtained using a computed tomography scanner	--	Age ≥ 50 , every 5 years
Fecal DNA*	Examination of the stool for traces of colorectal cancer DNA	--	Age ≥ 50 , interval uncertain

* Positive findings require follow-up colonoscopy.

In 2011, the Institute of Medicine's Committee on Standards for Developing Trustworthy Clinical Practice Guidelines noted that the divergent CRC screening recommendations from the USPSTF and ACS-MSTF-ACR contributed to confusion among clinicians and patients (IOM, 2011). The IOM committee argued that differences in these recommendations were likely the result of disparate development methodologies and committee composition (IOM, 2011).

To inform its work, the USPSTF drew on findings of a commissioned systematic review and benefit/risk simulation modeling (Pignone and Sox, 2008). The USPSTF methods were predefined, rigorous, and quantitative and they separated the systematic review process from that of guideline development (Imperiale and Ransohoff, 2010). However, Pignone and Sox (2008, p. 680) describe “some surprising choices” and missing analyses (e.g., cost/Quality Adjusted Life Years [QALY]) in the data modeling...In the joint ACS-MSTF-ACR guideline...“the process of evidence review was not clearly separated from the process of guidelines-making” and “no pre-stated process [was] used to translate evidence into recommendations, nor was the strength of recommendations graded” (Imperiale and Ransohoff, 2010, p. 5). The joint ACS-MSTF-ACR guideline document codifies two guiding principles that informed their recommendations: (1) the importance of one-time test sensitivity...given poor adherence to lower sensitivity program approaches, and (2) the primacy of colon cancer prevention in screening efforts (Levin et al., 2008). Commentaries on the guideline raise concerns about oversimplifications inherent in these decisions (Imperiale and Ransohoff, 2010) and note that this is the only guideline in which the American Cancer Society has adopted and expressed such guiding principles (Goldberg, 2008).

The USPSTF panel was composed of generalist physicians and methodologists (Imperiale and Ransohoff, 2010); the ACS-MSTF-ACR committee consisted of medical specialists and experts in the fields of radiology, gastroenterology, and oncology (Bottles, 2010; Goldberg, 2008). Bernard Levin, a member of the joint panel, remarked in *The Cancer Letter*, “It is extremely hard to bring disparate professional groups together, to have them operate totally out of objectivity, not because they are bad people, but because they see the world through different lenses. Everyone, in some respects, has their vested interests” (Bottles, 2010; Goldberg, 2008, p. 3; Jacques, 2010). Such sentiments have been echoed in multiple commentaries relating to clinical practice guidelines, with authors recognizing that bias extends beyond financial interests to include intellectual and emotional interests as well (Lederer, 2007). (IOM, 2011, p. 58-59)

Table 3 highlights the differences in panel composition and processes between the USPSTF and ACS-MSTF-ACR panels.

Table 3: Heterogeneity of Panel Composition and Processes (National Guideline Clearinghouse, 2010 and IOM, 2011)

	USPSTF	ACS-USMTF-ACR
Panel Category	Independent Panel of Generalist Physicians and Methodologists	Disease Specific Society and Medical Specialty Society Whose Members are Medical Experts in the Fields of Radiology, Gastroenterology, and Oncology
Source of Funding	United States Government	American Cancer Society, American College of Radiology, and US Multisociety Task Force on Colorectal Cancer
Reported Financial Conflicts with Panel Members	No Financial Conflicts Report	Financial Conflicts Reported
Methods Used to Analyze Evidence	Decision Analysis, Meta-Analysis, and Systematic Review with Evidence Tables	Review
Method of Validating Recommendation	Comparison with Guidelines from Other Groups, External Peer Review, and Internal Peer Review	Not stated

A recent study by Yabroff et al. (2010) examined physicians' recommendations for colorectal cancer screening and found that only 19.1% of physicians made "guideline-consistent recommendations across all CRC screening modalities." Clinician confusion linked to heterogeneity is one factor that might affect consistency of guideline use.

2.5 Health-Related Reports, Recommendations and Scientific Panels

Need for Synthesized Research Evidence Reports and Health-Related Recommendations

Despite the confusion caused by recommendation heterogeneity, there is a substantial need for recommendations and synthesized research evidence reports among many clinicians given the enormous volume of findings in the health literature. The number of randomized controlled trials published in MEDLINE grew from 5,000 annually in the early 1980s to 25,000 annually by the late 1990s (IOM, 2011). Furthermore, many “physicians have less than one hour per week to devote to reading the literature and limited skills in evaluating the quality of the research” (Albanese et al, 2009a, p. 1044).

Scientific panels can provide an invaluable service to clinicians by analyzing copious amounts of data, distilling research findings, and creating synthesized research evidence reports and health-related recommendations that “reduce inappropriate practice variation, enhance translation of research into practice, and improve healthcare quality and safety” (IOM, 2011, p. xi). Evidence reports and recommendations can also promote a more cost-effective use of health care resources (Grilli & Lomas, 1994), encourage discussion among caregivers about best practices, and serve to strengthen the professionalism of medicine (Khorasani, 2010).

Types of Reports, Recommendations, and Other Resources

There are different types of reports, recommendations, and other resources geared toward assisting not only health care providers, but also patients and their families, policymakers, and researchers in making better informed decisions. Although there is no universal agreement on their definitions, the following descriptions are used for the purposes of this study.

- **Clinical Practice Guideline** – A statement “to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances” (IOM, 1990, p. 38).

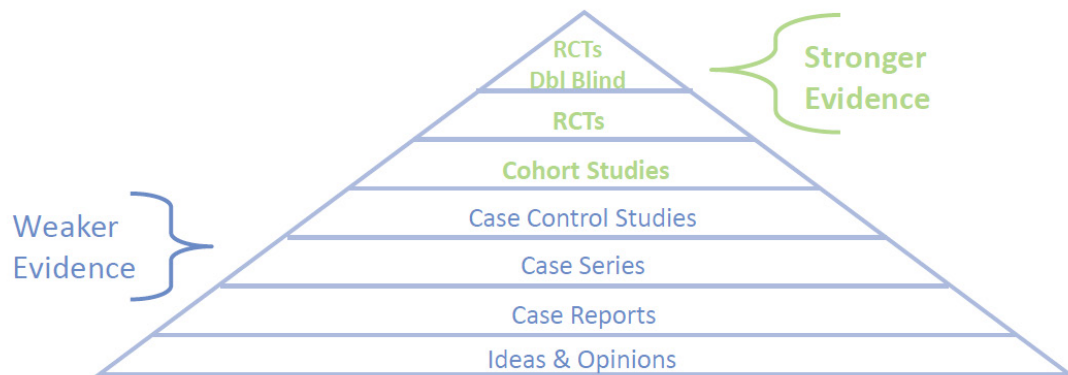
- Consensus Statement or Report – A document developed by a “panel of experts, usually multidisciplinary, convened to review the research literature for the purpose of advancing the understanding of an issue, procedure, or method” (O’Toole, 2003).
- Expert Advice – Guidance based on an individual expert’s experience or knowledge (Katzburg et al., 2009).
- Quality or Performance Measure – A criterion that can be used to “measure and quantify healthcare processes, outcomes, patient perceptions, and organizational structure and/or systems that are associated with the ability to provide high-quality care” (NQF, 2012).
- Recommendation – Guidance developed by a panel of experts that “highlights the opportunities for improving delivery of effective services” (AHRQ, 2013).
- Systematic Review – “A critical assessment and evaluation of all research studies that address a particular clinical issue. The researchers use an organized method of locating, assembling, and evaluating a body of literature on a particular topic using a set of specific criteria. A systematic review typically includes a description of the findings of the collection of research studies. The systematic review may also include a quantitative pooling of data, called a meta-analysis.” (AHRQ, 2014)

Additionally, although the term “evidence-based” is ubiquitous in the literature, its meaning varies. The description below will be used for this study.

- Evidence-based – “Applying the best available research results (evidence) when making decisions about health care” (AHRQ, 2014).

There is disagreement about what constitutes evidence, but the CDP utilized an evidence pyramid to distinguish between stronger and weaker evidence. See Figure 3.

Figure 3: Evidence Pyramid for the NIH Consensus Development Program. (NIH-CDP, 2011a)



Using definitions supplied by AHRQ (AHRQ, 2014) and ODP lecturer W. Scott Richardson, M.D. (Staus, Richardson, Glasziou, and Haynes, 2011, p. 1), this study will consider evidence-based clinical practice to be an integration of 1) the best research evidence available, 2) clinical expertise and, 3) the patient's unique values (i.e., preferences, concerns, expectations) and circumstances (i.e., individual clinical state and clinical setting). (AHRQ, 2014; Staus, Richardson, Glasziou, and Haynes, 2011, p. 1).

Sponsoring Organizations, Their Scientific Panels, and Recommendations

The National Guideline Clearinghouse has CRC screening recommendations from 17 organizations (see Appendix 2), eight of which are included in this study (see Table 3). The eight organizations are U.S.-based, national in focus, provide recommendations for people at average risk of colorectal cancer, and consider mechanisms to support common CRC screening modalities (i.e., FOBT, sigmoidoscopy, double-contrast barium enema, colonoscopy, computed tomography colonography).

In addition to these eight target organizations and their panels, three other groups are considered in this study based on their recently published work on CRC screening and their visibility among experts in the field.

- (1) The Cochrane Collaboration/Cochrane Colorectal Cancer Group

- (2) Centers for Disease Control and Prevention (CDC)/Community Preventive Services Task Force
- (3) Institute of Medicine (IOM)/ National Cancer Policy Forum

These 11 organizations and their scientific panels can be divided into four categories based on their “major designation or function” (NGC, 2012): 1) independent expert panel, 2) nonprofit organization, 3) disease specific society, and 4) medical specialty society. See Table 4.

Table 4. NCG-Listed Panels/Groups Included in the Study

Organization/Panel	Categories
1. National Institutes of Health, Consensus Development Program/ <i>State-of-the-Science Panel</i>	Independent Expert Panel
2. Agency for Healthcare Research and Quality/ <i>U.S. Preventive Services Task Force</i>	
3. Centers for Disease Control and Prevention/ <i>Community Preventive Services Task Force</i>	
4. American Cancer Society/ <i>Colorectal Cancer Advisory Group</i> :	Disease Specific Society
5. American Academy of Family Physicians/ <i>Commission on Health of the Public and Science</i>	Medical Specialty Society
6. American College of Radiology/ <i>Colon Cancer Committee</i>	
7. American Gastroenterological Association, 8. American Society for Gastrointestinal Endoscopy, 9. American College of Gastroenterology/ <i>U.S. Multisociety Task Force on Colorectal Cancer</i>	
10. The Cochrane Collaboration/ <i>The Cochrane Colorectal Cancer Group</i>	Nonprofit Organization
11. Institute of Medicine/ <i>National Cancer Policy Forum</i>	

See Appendix 3 for descriptions of the 11 organizations, their panels, and recommendations or conclusions.

Issues Regarding Recommendations

In 2011, an IOM report cited several factors that can erode confidence in health recommendations, including:

- Failure to convene a multi-stakeholder, multidisciplinary panel
- Unmanaged conflicts of interest among panel members
- Lack of transparency of panel methodologies
- Overall failure to use rigorous methodologies. (IOM, 2011)

The report also stated that “the quality of CPG [clinical practice guideline] development processes and guideline developer adherence to quality standards have remained unsatisfactory and unreliable for decades. Non-standardized development results in substantial variation in clinical recommendations” (IOM, 2011, p. 2).

Hutchinson et al. (2002) echoed concerns about the quality and transparency of panel processes by noting considerable variation in how evidence is appraised and how it is linked to subsequent recommendations. “At times, there was a lack of clarity in the information reported, such as a lack of clear distinction between evidence and expert opinion. Taken together, this meant that direct and accurate comparisons could not be drawn across the guidelines without the effort of going back to the original source evidence” (Hutchinson et al, 2002, p. 693).

Another factor that can attenuate the impact of recommendations is the issue of evolving evidence. Updates and changes to recommendations “as a result of new evidence suggest a certain level of uncertainty at any one time about the absolute efficacy...and may inadvertently contribute to poor compliance among physicians” (Holmes et al., 2004, p. 467). Moreover, Albanese et al. (2009b) stated that “vacillating practice guidelines, especially those that subsequent research reveals were harmful or unnecessary, are not uncommon and can demoralize physicians and their staff, dampening enthusiasm for making future changes...How can a physician know when a change needs to be made?” (p.1063).

Some clinicians are concerned that recommendations, specifically clinically practice guidelines, are ‘cookbook medicine’ (Conroy & Shannon, 1995) and question whether recommended interventions—tested under ideal circumstances with patients who met strict and narrow eligibility criteria—are relevant to certain practice settings and subpopulations (e.g., patients with comorbidities, patients who are socially and economically disadvantaged) (IOM, 2011; Lomas, 1994; Freidson, 1984).

“We have actually invented terms such as “effectiveness” versus “efficacy” research to capture the importance of the real world as opposed to that somewhat artificial, well-equipped, information-rich optimal practice world in which most research is conducted... There has been little regard, some would say overwhelming disregard, of the contexts from which patients come or the context in which the physician will practice” (Lomas, 1994, p. S95-S96).

Issues of importance, relevance, and appropriateness are particularly salient for primary care providers faced with an overwhelming number of recommendations, but with a paucity of clear evidence showing clinical effectiveness (Hutchinson, 2002). Grilli and Lomas (1994) also found that clinicians in more isolated primary care settings (e.g. family physicians, dentists, obstetrician-gynecologists) were less likely to follow guidelines than practitioners in specialty areas (e.g. cardiology, oncology), who often serve in secondary or tertiary centers where the transfer of research knowledge is ongoing.

There is also tension regarding the relationship between clinical guidelines and professional autonomy (Rappolt, 1997). “Despite being the quintessence of medical knowledge at the corporate level, guidelines diminish the clinical autonomy of individual practitioners, and therefore threaten medicine’s justification for its autonomy” (Rappolt, 1997, p. 977). Although it has been reported that guidelines reduce clinical freedom and physician satisfaction, others argue that resistance to guidelines, on the pretense of autonomy, may be used to mask inappropriate and inefficient clinical practice (Conroy, 1995). Professional tensions are discussed further in Section 2.6.

Lastly, the impact of health recommendations is often attenuated by a scientific panel's failure to consider and address implementation issues (Conroy, 1995).

The failure of clinical practice guidelines to achieve their potential in changing clinical practice to date can therefore be attributed, in part at least, to the fact that most current development processes do not treat implementation of the guidelines as an integral part of the development procedure. It is therefore now important to shift the focus from guideline development and to emphasize the need for guideline integration, which encompasses dissemination and implementation strategies, with provision made for evaluation, audit, feedback, and outcome measurement. (Conroy, 1995, p. 372)

Implementation plans are rarely incorporated or appended to recommendations and the context of their utilization has been largely ignored. However, understanding the relationships among patient, provider, and environmental factors is critically important, particularly from a programmatic or policy perspective (Phillips et al., 1998). Holmes et al. (2004) argued that the adoption of clinical guidelines may be affected by “the structure of the service delivery system and the degree to which decision supports exist to encourage and reward the practice of evidence-based medicine” (p. 467). This argument is supported by the research of Haggstrom & Bindman (2008) who found that physicians in HMOs were more likely to receive and follow guidelines than physicians in independent or medical group practices.

Although “the importance of research evidence in guiding clinical decision making is generally unquestioned intellectually, at a practical level patterns of medical practice often diverge from evidence-based recommendations, robbing patients of the benefits of medical research” (Oxman et al, 1995, p. 1424). Grilli and Lomas (1994) found a high degree of variation in compliance with practice guidelines and an average compliance rate of just 55%. In 2004, Holmes et al. noted that 56% of physicians reported that guidelines affected their practice of medicine, and of those affected, 66% reported the effects as positive.

The development of panel recommendations is an expensive and time-consuming process (Nast et al. 2004) and a waste of resources if the recommendations are not reliable and effectively

disseminated to stakeholders (Davis & Taylor-Vaisey, 1997). In response to “strong indications of the need to improve clinical decision making and healthcare quality” the IOM formed the Committee on Standards for Developing Trustworthy Clinical Practice Guidelines (IOM, 2011, p. xii). The 2011 IOM committee report, *Clinical Practice Guidelines We Can Trust*, included eight proposed standards for panels to follow, which address:

- (1) Transparency
- (2) Management of Conflict of Interest
- (3) Guideline Development Group Composition
- (4) Clinical Practice Guideline-Systematic Review Intersection
- (5) Establishing Evidence Foundations for and Rating Strength of Recommendations
- (6) Articulation of Recommendations
- (7) External Review
- (8) Updating.

A summary of the eight IOM standards is in Appendix 4. Although the IOM report focuses on clinical practice guidelines, the standards are often applicable to other types of reports, recommendations, and other resources.

2.6 Professional Practice and Control

Colorectal cancer screening recommendations are largely implemented by health professionals (e.g., physicians, physician assistants, nurse practitioners). This section covers literature on professions and professional control, provider practice and practice change, and professional societies—which work to educate, and advocate on behalf of, their members. Professional practice and control issues are included in this study because they can influence a clinician’s knowledge, support, and implementation of evidence-based recommendations.

Professions

There is no consensus on the definition of profession (Bureau & Suquet, 2009). Max Weber distinguished priests from sorcerers in the early 1920's using 11 defining characteristics of professions, including:

- (1) Power (ability to convince using rationale authority)
- (2) Doctrine, or general systematic knowledge
- (3) Rational training
- (4) Vocational qualifications
- (5) Specialization
- (6) Full-time occupation
- (7) Existence of a clientele
- (8) Salaries
- (9) Promotions
- (10) Professional duties
- (11) Distinctive way of life (professional culture). (Ritzer, 1975, p. 631)

In the 1930's Sir Alexander Morris Carr-Saunders and Paul Alexander Wilson identified the following professional properties:

Professions were organized bodies of experts who applied esoteric knowledge to particular cases. They had elaborate systems of instruction and training, together with entry by examination and other formal prerequisites. They normally possessed and enforced a code of ethics or behavior. (Abbott, 1988, p. 4)

Scholars today find attributes identified in the 20th century useful in understanding professional work. Gorman and Sandefur (2011) argue that four recurring professional attributes from the sociological 'golden age' of the study of professions are applicable to contemporary research. These attributes include 1) expert knowledge, 2) autonomy, 3) a normative orientation grounded in community, and 4) high status, income, and other rewards (Gorman and Sandefur, 2011).

Professional Control and Tensions

Eliot Freidson wrote extensively on the nature of professional control (who does what, under which circumstances, and for what purpose). In 1984, he argued that professional control was becoming more formalized, that stratification was paramount in the control of everyday professional practice, and that tensions were growing among the knowledge elite, administrative elite, and rank and file professionals.

- Knowledge Elite – An important difference between modern professions and crafts/guilds is the way the former systematically developed a relationship with universities and innovated through research, experimental practice, and theorizing. The knowledge elite of a profession conduct research, teach professionals in training, and produce the technical knowledge that is required to direct the work of the rank and file (Freidson, 1984).
- Administrative Elite – This group is comprised of executives, managers, and supervisors with official authority to issue directives to their subordinate rank and file colleagues. They “are accountable for the aggregate performance of the workers under them and they tend to have an organizational perspective... [They are] in a position to assert economic and administrative, but not technical or cognitive power” (Freidson, 1984, p. 15).
- Rank and File Professionals – These professionals are practitioners who are primarily concerned with “performing their work according to their own view of the intrinsic practical problems and of the necessary means of coping with them on a day-to-day-basis” (Freidson, 1984, p. 15).

Freidson (1984) noted that the knowledge elite is responsible for providing state-of-the-art information to public policy decision-makers and is often called to serve on committees that develop guidelines to govern professional practice. The administrative elite, which lack cognitive power or authoritative expertise, must rely on guidelines developed by the knowledge elite to formulate and evaluate the work of rank and file practitioners (Freidson, 1984). Resentments can occur between those more closely aligned with the profession (knowledge elite and rank and file

practitioners) and the administrative elite, which tends to have a strong allegiance to the organization they serve. Additionally, there is tension between ‘town and gown’, practitioner and academic:

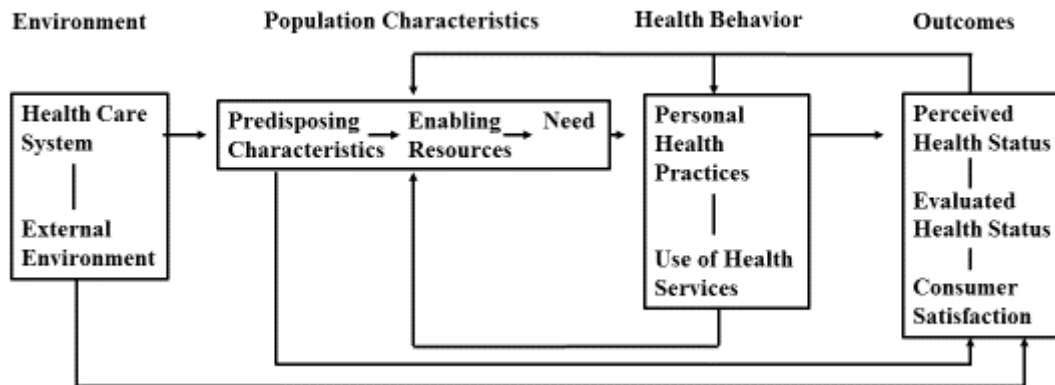
Since the standards of the knowledge elite are grounded in the abstract world of logic, scientific principles, and statistical probabilities rather than the concrete world of work, in experimental designs and controlled laboratory findings rather than in the untidy, uncontrolled arena of practice, and in circumstances that are considerably less subject to the constraints of time, money, equipment, and other resources than is true of everyday practice, it is not hard to understand the skepticism of the rank and file professional (Freidson, 1984, p. 16).

Determinants of Provider Practice

It has been estimated that there is a 17-year lag between scientific discovery and when most Americans benefit from research findings (Clancy, 2006). Even when strong scientific evidence supports certain practices (e.g. secondary prevention via cancer screening and detection) providers frequently do not perform those (Zapka et al, 2003). Many scholars argue that studying the context in which professional work is performed is key to understanding which professional procedures are implemented (Battista et al. 1986; Lomas, 1994; Davis & Taylor-Vaisey, 1997).

Lu Ann Aday and Ronald Andersen (1974) included contextual factors in a framework to study access to medical care. This model was initially developed to understand how and why families use health services (Andersen, 1995). Andersen revised the framework in 1995, creating an updated Behavioral Model for Healthcare Utilization. See Figure 4. This subsequent model shifted the unit of analysis to the individual and can be used to examine both patient and provider characteristics and behaviors (Andersen, 1995).

Figure 4: U.S. Behavioral Model for Healthcare Utilization. (Andersen, 1995)



Although the model is “one of the most frequently used frameworks for analyzing the factors associated with patient utilization of healthcare services”, its potential “for examining the context within which utilization occurs”—the role of the environment and provider-related factors—has been largely neglected (Phillips et al, 1998, 571). And yet these contextual variables are critical to understanding clinician practice.

The Behavioral Model for Healthcare Utilization identifies four domains:

1) Environment – This domain focuses on the milieu in which health care access occurs and is divided into two groups of variables (Davidson et al, 2004).

- Health Care System – These variables involve the labor and capital dedicated to health care (e.g., volume and distribution of providers, equipment, and health facilities) and their organization, or the manner in which resources are coordinated in the process of providing care (e.g., waiting times for appointments, office waiting times in reception areas) (Aday and Anderson, 1974).
- External Environment – These variables relate to broader social, physical, political, and economic conditions, such as societal norms, national health policies, and economic prosperity (Phillips et al., 1998).

Studies concerning environmental variables focus on systems or organizations as the unit of analysis (Aday & Andersen, 1974). However, because there has been a historical emphasis on individual factors in utilization studies, the result is “a dearth of information on the role of environmental factors” in influencing utilization (Phillips et al., 1998, p. 573).

2) Population Characteristics - This domain includes both patient and provider elements and can be divided into three groups of variables (Andersen, 1995).

- Predisposing Characteristics – These variables include age, education, ethnicity, gender (Stein et al, 2012), occupation, religion, and health knowledge and beliefs (Andersen, 1995). For patients, these variables describe the ‘propensity’ of individuals to use [or not to use] services (Aday and Anderson, 1974). For providers, predisposing characteristics “are intrinsic to who they are as people and how they view themselves and their roles in the system” (Albanese et al., 2009a, p. 1050). Zapka et al. (2003) noted that predisposing factors also include provider “knowledge of and agreement with clinical guidelines and protocols and assumptions about patients and their adherence” (p. 7).
- Enabling Resources – These reflect a patient’s means of obtaining needed health care using personal, family, and community resources (e.g., health insurance, income, regular source of care) (Lemming & Calsyn, 2004; Stein et al, 2012). For clinicians, enabling resources influence their capacity to provide care and include items such as reminder systems and decision-support tools (Oxman et al., 1995; Heltevik et al. 2000; Zapka et al., 2003; Haggstrom & Bindman, 2007).
- Need – This involves perceived need (i.e., a patient’s self-perception of a health condition) and objective or evaluated need (i.e. a provider’s medical diagnosis, which provides external validation) (Aday & Andersen, 1974; Honda, 2004).

Evaluated need is not simply, or even primarily, a valid and reliable measure from biological science. It also has a social component, and varies with the changing state of the art and science of medicine as well as according to the

training and competency of the professional expert doing assessment (Andersen, 1995, p. 3).

Clinical guidelines and recommendations can also affect the determination of need, by setting expectations that can influence a provider's judgment (Andersen, 1995).

3) Health Behavior - This domain refers to the direct actions taken by both patients and providers to maintain or improve health and is divided into two elements (Andersen, 1995).

- Personal Health Behaviors – Variables in this group include diet, exercise, and self-care among patients (Andersen, 1995) and physician recommendations for screening and other services (Phillips et al., 1998).
- Use of Health Services – This refers to the utilization of health services (e.g. number of doctor visits and total services provided) (Andersen & Aday, 1978).

4) Outcomes - This domain captures key subjective and objective outcomes.

- Perceived Health Status – This involves a patient's perception of well-being relative to the care they have received or to an illness they have experienced (Andersen & Aday, 1978).
- Evaluated Health Status – This involves the objective measurement of an individual's well-being (Andersen & Aday, 1978).
- Consumer Satisfaction – Consumer satisfaction concerns “attitudes toward the medical care system of those who have experienced a contact with it” (Aday & Andersen, 1974, p. 245). Dimensions of satisfaction may include perceptions about convenience of care, courtesy shown by clinicians, and the quality of the care received (Aday & Andersen, 1974).

Andersen (1995) noted that health care access is *effective* when utilization improves health status or consumer satisfaction; access is *efficient* when levels of health status or satisfaction increase relative to the amount of services received.

Access is *equitable* to the extent that predisposing demographic variables such as age and sex and the illness variables explain health services utilization. The demographic variables are included because of the well established relationships between illness

patterns and age and sex. Conversely, access is inequitable when use is explained by social variables such as race or education or by any of the enabling variables such as kind of health insurance coverage or number of physicians (Andersen & Aday, 1978, p. 535).

The Behavioral Model for Healthcare Utilization is useful from a programmatic or policy perspective because it explores the relationships among mutable and immutable patient, clinician, and environmental factors that facilitate or impede utilization (Andersen, 1995; Phillips et al. 1998). Demographic variables and social structure are considered to have low mutability, health knowledge and beliefs have medium mutability, and enabling factors (including insurance coverage and provider management tools) have high mutability (Andersen, 1995). By understanding which variables are most amenable to change, decision-makers can better plan interventions directed at providers, patients, and the environment (Andersen, 1995).

Practice Change

Health provider behavior is influenced by many factors. Battista et al. (1986) examined primary care physicians and their preventive practices (i.e. counseling, teaching, and screening) for breast, cervical, colorectal, and lung cancer. They found that colorectal cancer screening practices by physicians were influenced by mode of reimbursement (higher for salaried vs. fee for service), continuing education (higher among those who read journals and participated in classes), provider-related barriers (lower among those with lack of knowledge, or who perceived ineffectiveness or risk of procedures), and gender (women screened more frequently than men). Davis & Taylor-Vaisey (1997) argued that the adoption of guidelines was influenced by provider characteristics, patient factors, practice setting, incentives, and regulation. Among nurses specifically, Piper et al. (2008) noted that numerous provider, patient, and system-related factors affected the translation of guidelines into practice.

With the complex influence of multiple factors on clinician behavior, practice change requires more than a simple educational approach (Conroy & Shannon, 1995; Khorasani, 2010).

Education about an innovative health care recommendation may increase awareness and predispose providers to change, but “it is not sufficient to bring about actual behavioral change in the absence of an active implementation strategy appropriate to the setting concerned” (Conroy & Shannon, 1995, 372). Oxman et al. (1995) examined 102 studies of interventions aimed at changing provider practice, including:

- Educational Materials (distribution of recommendations using print, electronic, or audiovisual materials) – most studies showed that educational materials failed to influence change
- Conferences (participation of clinicians in conferences, workshops, lectures, or traineeships) – studies showed that conference participation failed to influence change
- Outreach Visits, also known as academic detailing, (use of trained individuals who provide information in the clinician’s practice setting) – studies showed that outreach visits reduced inappropriate prescribing and increased the delivery of preventive services
- Local Opinion Leaders (use of clinicians identified by their colleagues as educationally influential) – studies of the effectiveness of opinion leaders were mixed
- Patient-Mediated Interventions (interventions directed to patients with the aim of changing provider behavior [e.g., direct mailing to patients, patient education, and counseling]) – patient education improved management of diabetes mellitus; studies of other patient-mediated interventions were mixed
- Audit and Feedback (summaries of clinical performance obtained from medical records, electronic databases, observation, or patient comments) – studies showed mixed results
- Reminders (manual or computerized interventions that prompt clinicians to take an action) – studies showed mixed results
- Multi-faceted Interventions (a combination of two or more interventions) – “The use of a variety of interventions, such as audit and feedback, reminders, outreach visits, patient-mediated interventions or opinion leaders, has demonstrated changes in professional performance.” (p. 1427)

The authors determined that while most interventions were not successful in isolation, a combination of interventions improved provider performance, and to a lesser extent, health outcomes (Oxman et al., 1995).

In an evidence report for AHRQ, Marinopoulos et al. examined a variety of continuing medical education (CME) activities that “serve to maintain, develop, or increase the knowledge, skills, performance, and relationships a physician uses to provide services for patients, the public, or the profession” (AHRQ, 2007, p. 1). The CME interventions studied included the use of media (e.g., print, audio, video, internet), various educational techniques (e.g., academic detailing, demonstration, case-based learning, mentor/preceptor, programmed learning), and simulations (e.g., standardized patient, role play, task simulation, computer simulation). Of these activities, Marinopoulos et al. found that:

- Print interventions are either not beneficial or very weak in their ability to improve knowledge or attitudes.
- A multimedia approach is better than a single media intervention for improving knowledge, attitudes, and practice behaviors.
- Multiple techniques, that most commonly include case-based learning, are more likely to be associated with improvements in knowledge, attitudes, and practice behaviors than single techniques.
- Multiple exposures to CME activities produce better knowledge gains and attitudinal change. (AHRQ, 2007)

Davis & Taylor-Vaisey (1997) also found that a combination of two or more interventions had a greater impact on improving physician behavior and health care outcomes than single interventions.

Albanese et al. (2009a) reviewed many models of health provider change (e.g., Context-Input-Process-Products (CIPP) Model, Input-Transformation-Output Model, Coordination Implementation Model) and more general change process models (e.g., Transtheoretical Stages of

Change, Innovation Decision Process). Albanese et al. (2009b) argued that the further a provider moved along Everett M. Rogers' Innovation Decision Process, the more likely he or she is to adopt change. The authors also argue that CME is most likely to change behavior when:

- Barriers to implementation and maintenance are identified and providers are given the opportunity to develop solutions for their own practice
- The evidence in support of change is compelling and durable
- Respected colleagues, ideally local opinion leaders, adopt a change and encourage others to do so. (Albanese et al., 2009b)

Rogers' Innovation Decision Process is discussed in Chapter 2.7.

Professional Societies

Jordan, Espey, & Godfry (2010) noted that while guidelines issued from federal agencies are important, these recommendations alone are insufficient for improving patient care; "A strategy for widespread distribution and adoption of recommendations by relevant professional organizations and teaching institutions must be part of the plan from the start" (p. 1).

Many primary care providers are members of professional associations or societies, which "create networks of professionals through which information about innovations in a particular field are disseminated" (Newell & Clark, 1990, p. 199) and promote the exchange of ideas and foster "scholarship, research, teaching, policy development, professional development, and collegiality" (Nelson & Weeks, 2006, p. 411).

Frankel (1994) noted that professional societies, as organized self-governing institutions, "play a vital role in negotiating the boundaries of scientific freedom and responsibility" (1764) and serve the following functions:

- Mediate between their members and the social environment
- [Are] a strong voice in educating outsiders about the values and norms of the discipline and in securing support for their work

- Serve as custodians of their discipline's distinct body of knowledge, traditions, and professional norms
- Adopt standards and guidelines accompanied by a complementary program of education designed to reinforce those standards. (p. 1764)

Lowe (1972) asserted that the education of members, through annual meetings, scientific forums, and the publication of peer-reviewed journals, is a routine and traditional activity of the professional society. The education of professionals covers not only clinical issues, but broader ethical issues as well since professionals often have multiple and conflicting responsibilities (e.g., personal conscience, professional norms, and loyalties to colleagues, institutions, and larger society) and the public is increasingly ambivalent about the "growing interdependence among science, government, and industry...and suspicious of the scientific community's commitment to police itself" (Frankel, 1994, p. 1759).

Although professional societies profess strong support for ethical conduct, at both individual and organizational levels, many scholars identify conflict of interest as a key concern. Albanese et al. (2009a) argued that boundaries were becoming blurred between practice and industry and that the profit motive was putting physicians in conflict with their duty to provide quality care. Lomas (1994) reported that physicians who have a proprietary interest in a therapeutic or diagnostic facility prescribe 2-3 times more for such services than a physician with no proprietary interest. Kassirer (2005) wrote about the "complex web of financial conflicts of interest between professional societies and industry" noting that:

Conflicts occur at multiple levels. Some professional society officers and editors of official society journals are ongoing consultants to the pharmaceutical, biotechnology, and device industries. Some societies' clinical practice guideline committees are funded by industry and some of the participants in the guideline development process are paid industry consultants or speakers. Some official professional society materials are written by financially conflicted society members. (p. 401)

Partnerships between professional societies and the NIH are highly decentralized and vary based on NIH Institute or Center. Many of these collaborations support educational workshops, conferences, and scientific meetings (Butterfield et al. 2011), and are often funded through grant mechanisms (e.g., R13, U13). The National Cancer Institute (NCI) Office of Advocacy Relations frequently schedules meetings between leaders of professional societies and the NCI. One of the most structured models for public-private partnership was developed by the National Heart, Lung, and Blood Institute (NHLBI). The NHLBI invited representatives of professional societies, voluntary health organizations, and community programs to serve on program coordinating committees, such as the National Asthma Education and Prevention Program, the National Cholesterol Education Program, and National High Blood Pressure Education Program (NHLBI, 1999, 2012a, 2012b). Public-private partnerships can serve as a catalyst for practice change and promote the implementation of evidence-based recommendations.

2.7 Diffusion of Innovations

The creation of health care recommendations to improve clinical practice is a sterile exercise if significant attention is not given to their adoption (Davis et al. 2003).

Competing demands in a time-and resource-stressed system, coupled with profound external and internal changes in the structure of the organization and leadership, all work against process improvement. Efforts to redesign delivery systems, improve decision-support systems, and implement clinical information systems and patient self-management strategies must be undertaken within the broader understanding of diffusion as a social process. (Zapka et al., 2003, p. 8)

Elements of the theoretical framework, Diffusion of Innovations, by Everett M. Rogers can be used to explore the pathway from recommendation development to sustained adoption.

Diffusion and Dissemination

Rogers (2003) saw diffusion as a kind of social change and defined it as “the process in which an innovation is communicated through certain channels over time among the members of

a social system. It is a special type of communication, in that the messages are concerned with new ideas” (p. 5). Some scholars differentiate the terms *diffusion* (a spontaneous and passive spread of ideas) and *dissemination* (a planned and active process of spreading ideas to target audiences) (Lomas, 1993; Ciliska et al., 2005). Rogers; however, did not make this distinction and used diffusion to capture both the spontaneous and planned spread of new ideas. In this study, dissemination is used to describe the planned and active communication of new ideas from: 1) scientific panels to professional societies and 2) professional society leadership to membership. Diffusion will describe a broader process, which includes the development of new ideas, the communication of these ideas, and the five-stage process to adopt or reject them (Rogers, 2003).

Diffusion Elements

Rogers (2003) identified four main elements to diffusion:

- (1) Innovation – an idea, practice or object that is perceived as new by an individual or other unit of adoption (p. 12). Perceived attributes of an innovation include:
 - a. Relative Advantage – The degree to which an innovation is perceived as better than the idea it supersedes
 - b. Compatibility – The degree to which an innovation is perceived as being consistent with the existing values, past experiences, and needs of potential adopters
 - c. Complexity – The degree to which an innovation is perceived as difficult to understand and use
 - d. Trialability – The degree to which an innovation may be experimented with on a limited basis
 - e. Observability – the degree to which the results of an innovation are visible to others. (p. 15-16)

Rogers argued that innovations with less complexity and greater relative advantage, compatibility, trialability, and observability were more likely to be rapidly adopted than

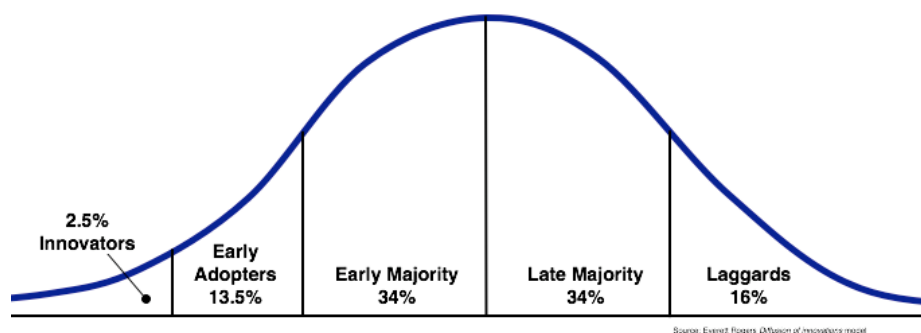
other interventions (2003). Other scholars have agreed with this position (Grilli & Lomas, 1994; Davis & Taylor-Vaisey, 1997; Albanese et al. 2009)

- (2) Communication Channels – These are means by which messages are passed from one individual to another. These channels can include mass media (e.g., newspapers, radio, television), interpersonal channels (which involve direct exchanges), and interactive communication channels, such as the Internet.
- (3) Time – This dimension involves the passage of individuals or groups through the innovation process.
- (4) Social System – Is “defined as a set of interrelated units that are engaged in joint problem solving to accomplish a common goal. The members or units of a social system may be individuals, informal groups, organizations, and/or subsystems” (p. 23).

Adopter Categorization

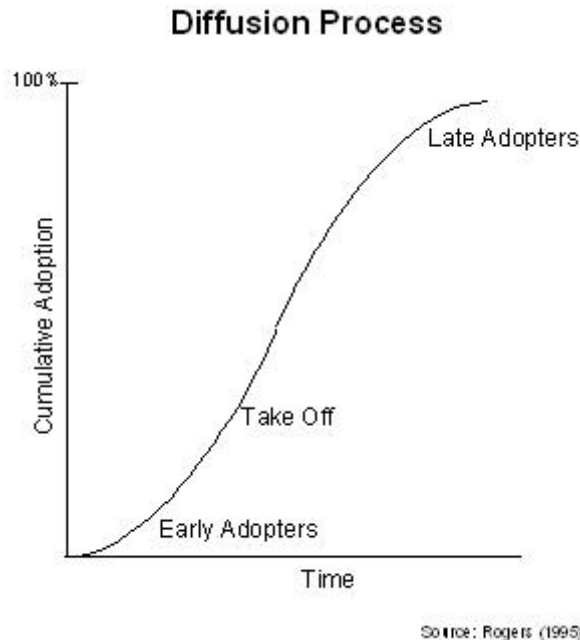
Innovativeness is “the degree to which an individual or other unit of adoption is relatively earlier in adopting new ideas than other members of the social system” (p. 37). Individuals in a social system adopt innovations at different times, and can be classified into one of five adopter categories based on their relative innovativeness: 1) Innovators, 2) Early Adopters, 3) Early Majority, 4) Late Majority, and 5) Laggards. “The adoption of an innovation usually follows a normal bell-shaped curve when plotted over time on a frequency basis” (Rogers, 2003, p. 272). See Figure 5.

Figure 5: Adopter Categorization on the Basis of Innovativeness. (Rogers, 2003)



“If the cumulative number of adopters is plotted, the result is an S-shaped curve” (Rogers, 2003, p. 272). See Figure 6.

Figure 6: Cumulative Number of Adopters in the Diffusion Process. (Rogers, 2003)



Innovation-Development Process

Rogers (2003) identified six steps in the trajectory of an innovation: 1) recognition of a need or problem, 2) basic and applied research, 3) development, 4) commercialization, 5) diffusion and adoption, and 6) consequences. He also specifically identified the point at which the NIH Consensus Development Program entered the process—step 5, diffusion and adoption.

Gatekeeping is controlling the flow of messages through a communication channel. One of the most crucial choices in the entire innovation-development process is the decision to begin diffusing an innovation to potential adopters (p. 155).

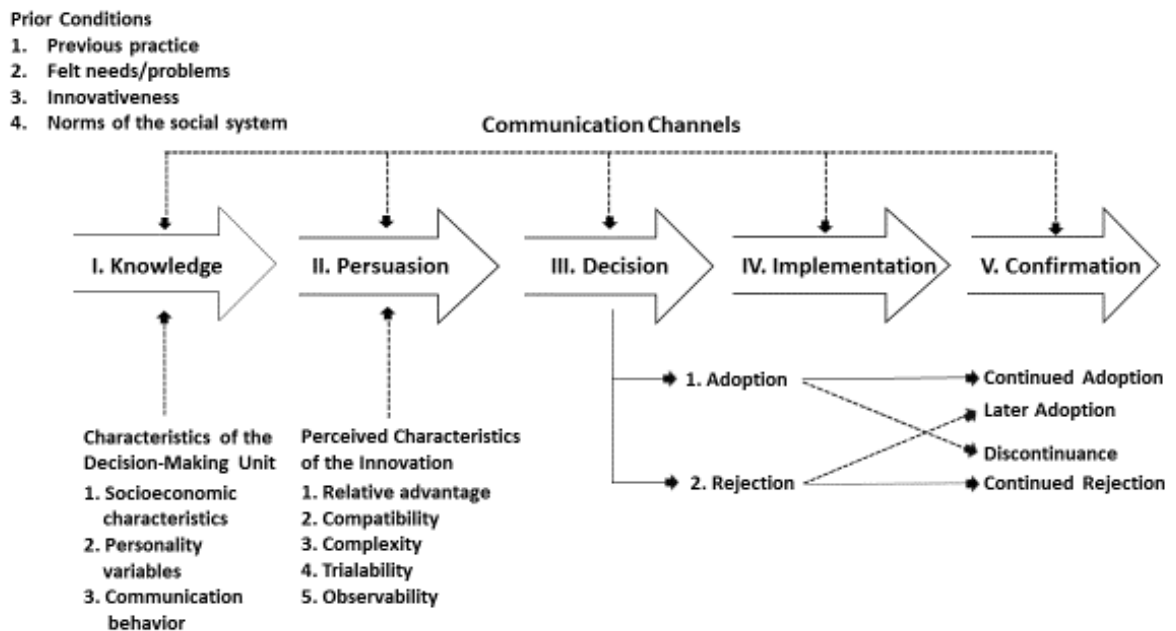
Innovation Gatekeeping – controlling whether or not an innovation is diffused to an audience of potential adopters – can occur in variety of ways...In medical diffusion there is a strong concern with exerting “quality control” over new technologies that spread to practitioners. This concern is understandable, given the possible threat to human life that might be involved in diffusing unsafe medical innovation to practitioners. The National Institutes of Health (NIH) conducts *consensus development*, a process that brings together

scientists, practitioners, consumers, and others in an effort to reach general agreement on whether or not a given innovation is both safe and effective...An NIH consensus conference typically ends with preparation of a brief consensus statement, which is then published by the U.S. government and widely disseminated to physicians in medical journals and by other means (p. 156).

Innovation-Decision Process

Individuals undergo a process when deciding to accept or reject an innovation. Rogers (2003) cites five sequential stages of behavior in the innovation-decision process: 1) knowledge, 2) persuasion (perceiving an innovation's attributes and forming a favorable or unfavorable attitude), 3) decision, 4) implementation, and 5) confirmation (reinforcing or reversing the decision to innovate). See Figure 7.

Figure 7: A Model of the Five Stages in the Innovation-Decision Process. (Rogers, 2003)



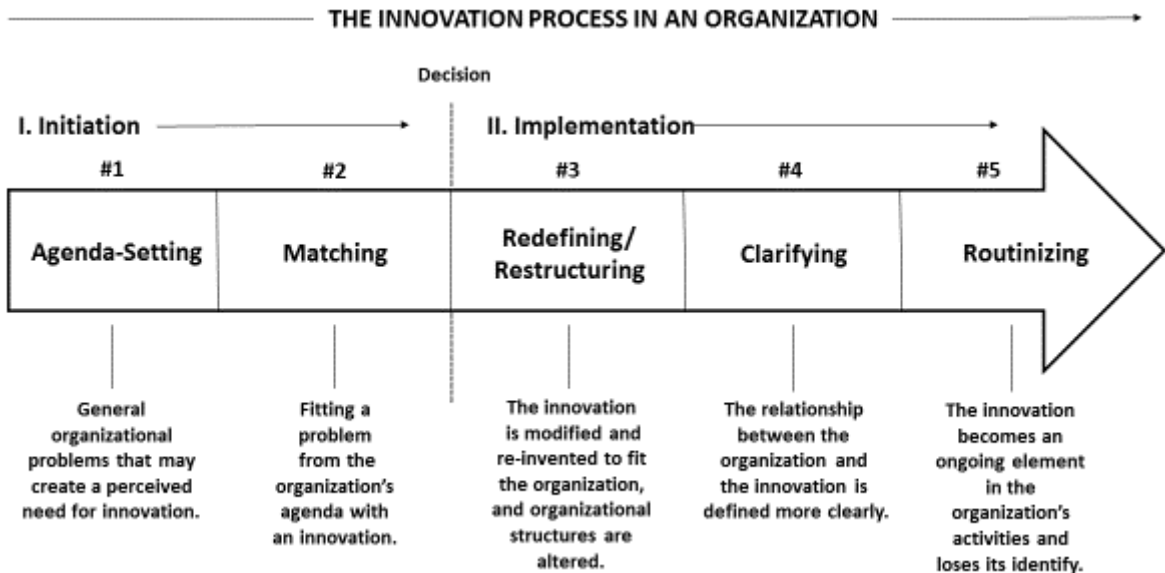
Innovation in Organizations

Organizations, like individuals, also undergo a five-stage process when deciding to accept or reject an innovation; however, the process for organizations is more complex because of organizational size and institutional bureaucracy (Rogers, 2003).

Rogers further categorized the five- stage process into two broad activities:

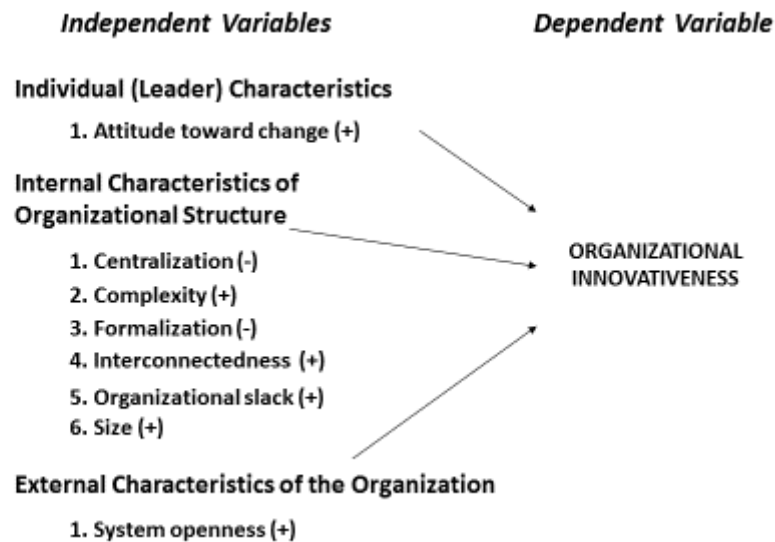
- (1) *Initiation*—consisting of all the information gathering, conceptualization, and planning for the adoption of an innovation, leading up to the decision to adopt use (Rogers, 2003, p. 421)
- (2) *Implementation*—consisting of all of the events, actions, and decisions involved in putting the innovation into use (Rogers, 2003, p. 424). See Figure 8.

Figure 8: Five Stages in the Innovation Process in Organizations. (Rogers, 2003)



Rogers (2003) also identified independent variables related to organizational innovativeness, including leader characteristics, internal characteristics of organizational structure, and external system openness. See Figure 9.

Figure 9: Independent Variables Related to Organizational Innovativeness. (Rogers, 2003)



2.8 Study Goal, Specific Aims and Research Questions

The overall goal of this study was to identify the role of federal scientific panels in promoting evidence-based practice and how federally-sponsored panels can better meet the needs of primary care providers and their professional societies for evidence-based reports and recommendations.

The study had three aims:

- (Aim 1) Describe the role primary care professional societies play in developing and/or disseminating evidence-based reports and recommendations.
- (Aim 2) Determine if the needs of primary care providers and their professional societies for evidence-based reports and recommendations are being met.
- (Aim 3) Describe the value that the federal government contributes to evidence-based practice.

To accomplish these aims, the study answered the five research questions below:

Research Question #1— What do professional society leaders and members know about organizations, scientific panels, and evidence-based reports and recommendations?

Research Question #2 — How do professional society leaders and members view organizations, scientific panels, and evidence-based reports and recommendations?

Research Question #3 — How do professional societies develop, support, and disseminate evidence-based reports and recommendations and what factors influence these activities?

Research Question #4 — What factors influence primary care provider implementation of evidence-based recommendations?

Research Question #5 — What role, if any, do professional society leaders and members believe the federal government should play in promoting evidence-based practice?

CHAPTER 3: METHODS

3.1 Overview

Research questions and study aims were addressed through content analysis of semi-structured telephone interviews conducted with 34 leaders and members from eight professional societies. Nonprobability, purposive sampling of knowledgeable experts enabled in-depth exploration of phenomena. The interview guide was developed using theory-driven concepts and theoretical frameworks, and pilot tested using cognitive interviewing techniques. The codebook included theory- and data-driven codes and was revised through an iterative process that included intercoder reliability assessments.

3.2 Study Population

The study population included leaders and members of U.S.-based primary care professional societies (or primary care segments of broader associations) that are national in focus and which address colorectal cancer screening issues through position statements or clinical recommendations.

An internet search of professional societies using the terms “health, professional organization, professional society, primary care, physician, nurse, medical, and nursing” yielded 26 medical and 27 nursing professional societies. See Appendix 5. Information was collected about each organization’s background, mission, position statements and clinical recommendations. Of these 53 organizations, only six medical societies had online documentation that they met the study’s eligibility criteria. The remaining 47 organizations were contacted by email. Within a week, 37 professional societies replied with information that disqualified them from the study. The remaining organizations (seven medical and three nursing societies), which did not respond to the email inquiry, were contacted by telephone. After discussion with a staff member from each

organization, it was determined that none of these professional societies met the study's eligibility criteria. See Appendix 5.

The six physician professional societies that met the study's eligibility criteria are listed in Table 5. Although no physician assistant or nursing organizations met all the study criteria, it is important to understand how physician assistants and nurse practitioners view recommendation developers, how their professional societies disseminate recommendations, and how federally-sponsored panels can better design and communicate their recommendations to these stakeholders. Therefore, the largest nurse practitioner and physician assistant societies identified through the internet search were also included in this study and are listed in Table 5.

Table 5. Health Care Professional Societies Involved in this Study

Physician Professional Societies	Physician Assistant Professional Societies	Nurse Practitioner Professional Societies
American Academy of Family Physicians (AAFP)	American Academy of Physician Assistants (AAPA)	American Academy of Nurse Practitioners (AANP)
American College of Physicians (ACP)		
American College of Obstetricians and Gynecologists (ACOG)		
American Medical Association (AMA)		
American Medical Women's Association (AMWA)		
American Osteopathic Association (AOA)		

3.3 Sampling

The study used nonprobability, purposive sampling of individuals within the professional societies listed in Table 5. In purposive sampling, the emphasis is on in-depth understanding, not generalization from a sample to a population (Trochim, 2006, Patton, 2002). Purposive sampling involves the selection of information-rich or illuminative cases that provide insight about a phenomenon; in the case of this study, it included persons with known expertise in their field and respected recognition in their professional society (Patton, 2002; Trochim, 2006).

Trochim (2006) divides purposive sampling methods into five subcategories: 1) expert, 2) quota, 3) snowball, 4) modal instance, and 5) heterogeneity. This study utilized expert and snowball sampling of professional society leaders and members.

3.4 Recruitment

The President/Chief Executive Officer (or a Board Member) of each professional society was mailed:

- An invitation letter
- A description of the study
- Letters of support signed by the Director of the NIH Office of Disease Prevention and a lead researcher from the NCI Division of Cancer Control and Population Sciences
- Two copies of the consent form (one to sign and return; one to keep)
- A response sheet to indicate interest and/or willingness to participate in the study
- A pre-stamped envelope to return the consent form and response sheet. See appendices 6-11.

Those who did not respond within six weeks were sent a follow-up email and telephone calls were placed to nonrespondents at ten weeks.

Each interviewee was offered a \$60 stipend in appreciation for their time and participation in a one-hour interview. Twenty-six leaders were invited to participate in the study; one did not respond and seven (all of whom were Presidents or Chief Executive Officers) provided the names of staff members who would be willing to participate. Leaders also identified one or more members of their professional society who would serve as information-rich cases for the study. Eighteen members were invited to participate; two members (from different organizations) did not respond. Table 6 shows the number of participants from each professional society.

Table 6. Sampling for Each Professional Society in this Study

Professional Society	Leader Interviews	Member Interviews
American Academy of Family Physicians	3	3
American College of Physicians	3	2
American College of Obstetricians and Gynecologists	3	3
American Medical Association	3	1
American Medical Women's Association	1	1
American Osteopathic Association	2	2
American Academy of Physician Assistants	2	2
American Association of Nurse Practitioners	1	2
Total	18	16

3.5 Qualitative Approach

Qualitative inquiry is not a monolithic approach to research; there are several qualitative theoretical traditions (e.g., positivism, symbolic interaction, grounded theory) (Patton, 2002).

This study was guided by systems theory.

Systems Theory

Patton (2002) notes that systems are greater than—and different from—their interconnected and interdependent parts. Although it is useful to analyze parts in isolation, it is insufficient if the goal is to understand the real-world complexities of whole entities and what influences them (von Bertalanffy, 1950; Patton, 2002; Bonn, 2005). Rather than examining an entity as a “splintered conglomerate of dissociated parts” (Bonn, 2005, p. 338), systems theory is a holistic perspective which seeks to answer: “How and why does this system as a whole function as it does?” (Patton, 2002, p. 121).

In this study, the professional society was the primary system to be examined. Interviewing leaders and members provided insight into the “internal and external dynamics of organizational life”, as well as how organizations are embedded within the larger, more complex system of health care (Bonn, 2005, p. 338). The study’s use of Diffusion of Innovations (to explore organizational systems, i.e. professional societies) and the Behavioral Model for Healthcare Utilization (to explore the broader environment that influences provider practice) dovetailed well with a systems theory approach.

3.6 Data Collection and Analysis

Data Collection

Data was collected through semi-structured interviews with open-ended questions; the researcher set an initial agenda in terms of the topics discussed, but the interviewee’s responses determined the kinds of information gathered about these topics (Green & Thorogood, 2006). The semi-structured interviews also permitted new questions based on interviewee responses and enabled the exploration of perceptions and opinions about complex issues (Barriball & White, 1994). The process provided the freedom to explore issues that emerged in discussions which might have been missed through more tightly scripted interviews (Beatty & Willis, 2007, p. 297).

The study involved a cyclical process of sampling, data collection, and analysis. As information was gathered and scrutinized for themes, it provided guidance regarding additional questions and participants. This process continued until no new concepts emerged from the data—a point of saturation was reached (Green & Thorogood, 2006).

The semi-structured interview guide was pilot tested with three leaders and two members using cognitive interviewing techniques utilized by the NCI, Division of Cancer Control and Population Sciences, Applied Research Program. These techniques involve administering the instrument while collecting additional verbal information to identify and correct any problems

with the interview questions (Beatty & Willis, 2007). As part of the pilot testing, cognitive probes were used to assess:

- Clarity of interview guide questions (e.g., What does this term mean to you?)
- Difficulty or appropriateness of questions (e.g., Was it easy or difficult to answer this question? Please tell me more about that.)
- Respondent knowledge (e.g., How much would you say you know about this topic? Are you involved in this process? If so, how?)
- Respondent computation (e.g., What factors did you think about when answering this question?)

Two changes were made to the interview guide based on feedback from the cognitive interview participants: an eighth item was added to a list of issues facing providers during clinical decision-making, and one question was changed to ask what characteristics made federal recommendation developers *untrustworthy* as well as trustworthy.

Since many interview participants were outside the Washington, D.C. metropolitan area, interviews were conducted by telephone. Each interview lasted approximately 45 minutes to one hour. The first eight interviews were conducted in tandem by the lead investigator and an experienced interviewer contracted to the ODP through IQ Solutions, a private firm specializing in communications and health information. The joint interviews provided the lead investigator with additional training prior to the broader administration of the instrument. To improve reliability, all interviews were recorded and transcribed (Green and Thorogood, 2006) using the NIH's telecommunications contractor, MyMeeting Conferencing Solutions.

Data Analysis

Content analysis was used to identify core consistencies and meanings from the data (Patton, 2002). Although data analysis was guided by some theory-derived concepts and theoretical

frameworks (e.g., Diffusion of Innovations, Behavioral Model for Healthcare Utilization), the data were also examined for patterns and emergent understandings (Patton, 2002).

Analysis was conducted following several steps noted by Green and Thorogood (2006) and Barnard (2010):

- (1) *Familiarization* – Fieldnotes or transcripts were re-read “until the researcher is closely familiar with them in their entirety” (p. 184)
- (2) *Thematic analysis* – Themes were identified and served as coding labels
- (3) *Indexing* – Codes were systematically applied to the entire data set and comparisons were made within and between cases
- (4) *Charting* – Data was rearranged by theme
- (5) *Mapping and Interpretation* – Relationships among themes and cases were explored

The following methods were used to bolster the study’s rigor of analysis (Green and Thorogood, 2006):

- A clear account of procedures (an audit trail) was developed to promote transparency
- Validity was promoted by analyzing deviant cases and disconfirming data, and by providing sufficient context so others could judge interpretations
- Several transcripts were analyzed by two coders at the beginning, middle, and end of the study to maximize reliability
- Data between and within cases were examined to explore the contextual meanings and strengthen comparison
- Theoretical assumptions, how they shaped the study, and how values “have both made possible the research...and constrained it” are discussed in Chapter 5 and promote reflexivity. (p.195)

Computer assisted qualitative data analysis software (ATLAS.ti 7) was used for data management to assist in coding, retrieving, comparing, and linking data from 900 pages of transcripts (Patton, 2002). A codebook was developed using theory- and data-driven codes (DeCuir-Gunby, Marshall, & McCulloch, 2011) and included the code abbreviation, code name, code definition, and examples for more complex concepts (Berends & Johnston, 2005).

Transcripts were coded independently; the coders met to check for agreement and came to

consensus with any differences; and the codebook was revised three times. After each codebook revision, all transcript coding was updated to reflect new or revised codes. Intercode reliability was determined using this formula:

$$\text{Reliability} = \frac{\text{\# of agreements}}{\text{Total \# of agreements + disagreements}}$$

The coders met four times; Intercode reliability was 76%, 86% (at the beginning of study), 90% (middle of study), 93% (end of study).

3.7 Human Subjects Considerations

This research study adhered to the guidelines prepared by the Johns Hopkins Bloomberg School of Public Health, Committee on Human Research (CHR) and the National Institutes of Health, Office of Human Subjects Research (OHSR). The protocol for this study was vetted by CHR and OHSR prior to any contact with human subjects.

There were no direct benefits for participation in the study. Indirect benefits included the improved development and messaging of evidence-based recommendations by the ODP to professional societies and primary care providers.

There was minimal risk associated with being a participant in the study. Some identifying information (including name, address, and phone number) was collected; therefore, securing confidentiality was a key concern. To guard against breeches in confidentiality, participants were assigned a unique study code number and all interview transcripts and notes were enumerated by code number. The linkage between code number and identifiable data was maintained on a password protected server with access limited to study administrators. Identifying information was kept separate from other documents that held participant data (e.g. interview notes, transcripts). All hard-copy data were stored within secure offices at IQ Solutions and the NIH.

At the beginning of each interview, the interviewer referred the participant to the consent form, which included a description of the study; potential risks and benefits for participating; the

right to end the interview at any time; steps taken to protect confidentiality; procedures for handling data; and whom to contact with any questions regarding the study. Participants were asked for their permission to record the interview and if they had any questions. Audiofiles were destroyed 30 days after each interview and any mention of indentifying information during an interview was stricken from transcripts. De-identified data were used for all analyses and reporting of results.

CHAPTER 4: RESULTS

4.1 Overview

This chapter presents study results from 34 semi-structured telephone interviews. It begins with participant and professional society characteristics and the latter's association with innovativeness. This is followed by an examination of views on, and support for, evidence-based recommendations and practice. Next is a report on awareness, knowledge, attitudes, beliefs, and utilization of scientific panel reports and recommendations. The chapter concludes with views on the value the federal government contributes to evidence-based practice, and suggestions for how federally-sponsored panels can improve their composition and processes; make recommendations more readable, acceptable, and feasible; and strengthen partnerships with stakeholders.

4.2 Study Participant Characteristics

The 34 participants in this study came from a variety of geographical regions and held different career and leadership roles. Table 7 shows demographic characteristics of the study participants.

Table 7: Demographic Characteristics of Study Participants

	No. of Participants	
	Leaders n=18	Members n=16
Sex		
Female	10	9
Male	8	7
Geographical Region		
Midwest	6	2
Northeast	2	1
South	10	9
West	---	4
Area of Professional Society Leadership		
Executive Vice President	1	---
Board Member	1	---
Clinical Practice	2	---
Science and/or Research	3	---
Education	6	---
Government Relations or Policy	3	---
Other	2	---
Type of Clinical Training		
Adult Primary Care	---	1
Family Medicine	---	5
Internal Medicine	---	7
Obstetrics and Gynecology	---	3
Career Role of Member		
Academician/Clinician	---	7
Academician/Administrator	---	1
Clinician	---	5
College Administrator	---	1
President/Founder of Advocacy Organization	---	2

Among members, years of career service ranged from 1 to 38 years, with a mean of 22 years.

4.3 Professional Society Characteristics and Innovation

The professional societies included in this study were membership organizations whose objectives largely focused on promoting patient health, enhancing the practice environment and education of its members, and advocating for changes in health care policy. Their size ranged from a staff of <10 to >900 people, and membership ranged from 3,000 to nearly 218,000 professionals.

Professional societies often have shared governance and formalized procedures, and maintain highly knowledgeable members.

Governance in these societies was often shared among:

- An Executive Board, Board of Directors, Regents, or Trustees
- Executive staff
- Official committees, commissions, or subspecialty boards

(Foci included strategic planning, administration, professional practice, research, ethics, education, and advocacy.)

and

- A Congress, House of Delegates, or Board of Governors—consisting of members from constituent chapters and districts, and sometimes other professional societies and state medical associations

(Their charge was to make recommendations; some had voting authority to endorse or reject proposed policies and resolutions.)

When discussing centralization, or the “degree to which power and control in a system are concentrated in the hands of a relatively few individuals” (Rogers, 2003, p. 412), most respondents described their societies as being a hybrid, with some decisions (particularly administrative ones) made by a few, while other decisions incorporated not only senior executive leadership, but also representatives from constituent chapters and districts. Complexity, the degree to which an organization’s members possess knowledge and expertise (Rogers, 2003) was high across all societies given the education, formal training, and degree of professionalization among its members. Formalization, the degree to which an organization emphasizes the following of rules and procedures (Rogers, 2003) was high among most organizations.

Size and system openness varied, but were associated with self-reported innovativeness among professional society leaders.

System openness, the degree to which members of a system are linked to other individuals external to the system (Rogers, 2003), varied substantially among societies. Organizations with greater staff and financial resources were able to designate official liaisons to several external scientific panels and organizations. Size and system openness were also associated with self-reported innovativeness among professional society leaders. Larger, more open system

organizations were more likely to be self-described as trailblazers, often because they have the resources to develop their own health reports and recommendations or they have processes in place to review and endorse the work of others. For example, a leader at a large organization with a very sophisticated process for developing clinical recommendations stated:

Oh definitely, [we're a trailblazer]. The [professional society] is a very well respected organization when it comes to evidence-based medicine and evidence-based clinical practice guidelines and other programs as well. I think people are very well aware of how closely we stick with the scientific evidence and how rigorous our program is when it comes to the development of guidelines. --- Professional Society Leader #1

Smaller, less open systems were more frequently self-described as “followers” who tended to wait for larger organizations to weigh in on clinical issues before taking a position themselves.

If it's something that is clinical, we're probably waiting for endorsements from the more reputable or more involved larger organizations—say the Institute of Medicine or the American Cancer Society. --- Professional Society Leader #2

When we make [clinical] recommendations, we feel like they're kind of tried and true already. If there was something new and different that needed to be looked at more in-depth, we would probably hold back a bit. --- Professional Society Leader #3

One exception was a smaller society that did not wait before releasing statements on certain key issues.

I definitely feel like the intention is that we're a trailblazer. We're not necessarily sitting back and waiting for the specialty societies. One example of that is last year there was some fuss about ultrasounds before abortion. The [professional society] did not sit back and say, “Let's see where everybody is before we weigh in.” --- Professional Society Leader #4

Although smaller, less externally connected organizations were less likely to take clinical positions before larger societies, the smaller groups were proactive in disseminating information, often on professional issues important to their members.

We're very good disseminators of information. Whenever [the USPSTF comes] out with recommendations, we always post them. We don't take a position on them, but we always

disseminate the information to our members, and they can make their decisions as to what they want to do. --- Professional Society Leader #5

The clinical information from [our professional society] tends to be less prescriptive and sort of descriptive about what other people are doing. We may contact another society and say, “Hey, how is this done?” [The information we produce] is more specific to our profession—organizational and structural issues, staffing models, things like that. --- Professional Society Member #1

Many respondents expressed a desire for their organization to become more innovative and noted barriers that hindered this objective.

One of the things that holds us back a little bit, at least in appearance, is that all of our recommendations come out via our journal. It’s not an official [professional society] position until it’s published there, and the process to get this done takes months. Although we know the recommendations we’re going to make, they sometimes are six to eight months behind others. Our process [causes] delay, so it appears frequently that we are followers for many guidelines. We would rather be leaders, but that’s the way it appears sometimes and we get criticized for that from our members. --- Professional Society Leader #6

The democratic process makes us slower and reactive rather than proactive and innovative. --- Professional Society Leader #7

[One barrier] is probably bandwidth. I mean, there’s only so much you can do, and each one of these things is difficult. --- Professional Society Leader #8

A few participants did not self-identify their organization as either trailblazers or followers. One respondent said the focus of their organization was not the propagation of new ideas, but rather to focus on “important issues that are needed by our members...we pay attention to our mission.”

Other respondents echoed a focus on topics important to members or central to their organization’s mission.

It just depends on what you’re talking about. If it’s a topic that’s central to what we’re working on, and it’s an evidence-based recommendation, I don’t think we would ever wait and just passively see if it was becoming popular. If it’s something way external to

*our focus, we're unlikely to push it because we don't want to become too diffuse. ---
Professional Society Leader #9*

4.4 Views on Evidence-Based Recommendations and Practice

There were differing views on the meaning of “evidence-based”, but there was broad agreement on its scientific underpinning and the importance of conducting “evidence-based practice.”

General definitions described evidence-based recommendations and practice as having “some scientific merit” and being “based in evidence, things that we have studied”, and “based on good science, peer-reviewed publications.” More detailed responses expanded on these descriptions by adding procedural or outcome-based components, which often involved the patient.

I think evidenced-based medicine is actually backed up by data, solid studies...we don't do something just because it seems to make sense, or it sounds right, or other people think it sounds right. We do this because there are studies that show this works or works better. --- Professional Society Member #1

Evidence-based recommendations integrate the best available evidence from clinical studies with the physician's experience, knowledge of pathophysiology, and understanding of patients' views and preferences. --- Professional Society Member #2

Evidenced-based practice involves consolidating and compiling various pieces of research that are applicable to the question at hand and coming up with the best recommended treatment for a patient. --- Professional Society Member #3

Evidence-based practice integrates the highest level of medical evidence based on studies, hopefully—randomized trials and prospective trials, or sometimes expert opinion or consensus opinion—into the bedside management of patients. --- Professional Society Member #4

Evidence-based recommendations are based on a systematic, unbiased consideration of the available evidence. --- Professional Society Leader #2

Rather than experiential practice, evidence-based practice is based upon proven outcomes and proven evaluation of methods. That's a major change. We've gotten away

from individualized practice and experiential practice into epidemiologically-based practice and outcome-based practice. --- Professional Society Leader #10

Although the term “evidence-based” holds different meaning for different people, there was wide agreement among participants that conducting evidence-based practice and recommendations was very important for most primary care providers.

For me, personally, it's is highly important. I just care so much about the care I provide. I would feel uncomfortable not providing evidence-based care. --- Professional Society Member #5

It's absolutely important. We have fallibility in our own thinking, the same as what you see in any non-clinician, and evidence-based guidelines help us recognize those frailties in our own logic and reasoning. --- Professional Society Member #6

A few participants cited that evidence-based practice and recommendations were less compelling to a subset of older, traditionally trained clinicians.

It's a big challenge for physicians my age and the Boomer physicians, because all of us were educated experientially. The educators provided you with, “This is the way to do it” and that's the way you learned to do it. There's a sector amongst the older physicians who really think of what they do as an art rather than a science. --- Professional Society Leader #10

Although conducting evidence-based practice was widely viewed as important, some respondents noted that standards of care and accessibility of resources influenced the ability of clinicians to implement evidence-based recommendations.

If your professional society says get super-special MRIs on everybody and you don't have a super-special MRI in your community, then you wouldn't be applying it. --- Professional Society Member #5

Regional changes in the standard of care are not supported by the evidence. With crafting a guideline, we need to be aware of differences in regional resources and allow for flexibility. --- Professional Society Member #6

A patient's values and circumstances should be considered when weighing the benefits and harms of evidence-based recommendations.

Many respondents noted that evidence-based screening recommendations were geared toward asymptomatic, at average-risk populations and that clinicians needed to consider the individualized needs of their patients when making decisions about implementing evidence-based recommendations.

Is this really going to help? Not everything is going to help every individual in each instance—it's the best practice for the biggest body, the biggest bang for your buck. Then you have to individualize the evidence-based guidelines and recommendations at the patient level to make sure it's actually something that's going to be applicable and doable for your patient. --- Professional Society Leader #11

Sometimes there's some judgment that has to be applied when using evidence in practice and using it in the context of an individual patient's life when other priorities might exist. --- Professional Society Member #6

Sometimes the recommendation might make scientific sense, but that does not necessarily mean it makes sense for an individual in a particular situation. --- Professional Society Member #7

Some participants discussed how evidence-based recommendations would change with evolving technology, from “What should we do for the average person?” to “What should we do for individuals with these specific characteristics?”

We're now moving into an era that's going to be more challenging because we will know more and more about the individuality of medicine; because we'll know more about genetics, epigenetics, and the influence of specific aspects of the environment. We will gradually move into a realm where there is no average person. I don't think our evidenced-based medicine methodologies are up to that at this point. So I often try to think about what lies beyond what we now think of as evidenced-based medicine, which is very much tied to what should we do for the average person—which we assume is almost everybody and then there are these five exceptions. --- Professional Society Leader #9

High quality, evidence-based recommendations were considered valuable, but not always available.

Some participants noted that high quality evidence, [based on the evidence pyramid] is sometimes absent from the literature, especially for rare conditions. This is a challenge for primary care providers and patients seeking information and clinical options.

There have been questions that I've had and I've looked for evidenced-based answers and not been able to find them. --- Professional Society Member #1

Well, sometimes there's not a lot of evidence, but you don't need to know that if you run off a cliff you're going to die when you fall off. Sometimes, we're just going to have to use a little common sense. --- Professional Society Member #3

Evidence-based practice is informed by data, when it exists. I mean, as you know, there's not data on everything. --- Professional Society Member #8

Ideally, randomized trials would be the best. But if not that, then looking at the type of trial that was done and how they controlled for as much bias as possible. Unfortunately we see a lot of [rare conditions] in my practice, and sometimes you actually have to go off case reports. Whether or not it's evidence-based, I'm not sure that you can actually say that, but you're going off as much information as you have and that's the best that you can do. --- Professional Society Member #9

There are situations where you cannot find good evidence, but you end up with a patient. So the physician does need to know how to take care of that patient at that point in time. They can't just say, "Well, I don't really have good evidence from randomized controlled trials, so I can't really do anything." In that case, of course, the evidence from some experts may kick in. But that's only in the absence of good evidence. If there is good evidence, I think we need to stick with it and avoid expert-based opinion. --- Professional Society Leader #1

One member noted that the scarcity of evidence in certain scientific areas was due in part to economic pressures.

I think some of the difficulty is we fund a lot of research based on a commercial goal. It's just hard to get studies on things where there's not necessarily a profit for some company. --- Professional Society Member #1

Views varied on what was an acceptable level of evidence, but many supported a transparent process to assess the quality of evidence and strength of recommendations.

I hear somebody say, “This [decision] is based on evidence-based recommendations.” And I’m thinking to myself, “It’s just not that good of evidence.” --- Professional Society Leader #6

We do use the term evidenced-based, and what we’re generally referring to are recommendations that can be supported by high quality clinical studies. But, of course, recommendations have different levels of evidence support—the highest support coming from a large number of randomized clinical studies or systematic reviews, and the lowest level—and I hesitate to use the word evidence—in terms of expert opinion and consensus. We certainly make a real effort to distinguish between the levels of evidence supporting our recommendations, and in our guidelines we use the GRADE process in order to do that. --- Professional Society Leader #12

We define evidence-based practice based on the level of evidence from the particular sort of study, really aiming for the randomized controlled prospective trial being the gold standard. We look at all of the current peer reviewed data that’s out there and then we quantitate it based on whether it’s randomized, prospective, retrospective, or whether it is a summary of expert opinion, so when people read what we are saying they know what the level of evidence was for the statement. --- Professional Society Leader #13

We look to see the process that was used - was it a Delphi process or consensus? We look to see whether they actually rated the evidence. We also look for ratings of their recommendations. That is a little tough sometimes because different groups have different rating systems. --- Professional Society Leader #14

I am looking for a transparent process that involves systematically searching for and appraising the relevant evidence. I think a systematic review should always be conducted with the recognition that oftentimes even the best systematic review is not going to answer all of the questions that need to be addressed. --- Professional Society Member #2

I want someone to tell me how they ranked the evidence, and then follow that systematically through their analysis. --- Professional Society Member #5

Several participants discussed concern with expert-based (testimony by a single expert) or consensus opinion (testimony and agreement reached by more than one expert).

When it's a consensus guideline you really have to be suspectful. By consensus, I mean this is our best recommendation as opposed to an evidenced-based guideline. ---

Professional Society Leader #7

I think the dilemma is how to be truly evidenced-based and within that—how do you capture or consider expert opinion? What place, if any, should it have in the evidence tree? --- Professional Society Leader #9

Some may consider collective expert opinion or common practice to be evidence, but we actually don't. --- Professional Society Leader #15

Some respondents were more accepting of expert-based or consensus opinion as part of the evidence tree when combined with higher levels of evidence.

There are certain levels of evidence and I think that it's always good to have a mix of that. I think that it is valuable to have expert opinions; however, I don't put as much emphasis on that as I would randomized controlled trials. --- Professional Society Leader #3

I tend to like expert opinion...they've already worked with patients, they've been clinical. They're looking at the data and thinking about how that data applies to patients. Systematic review to me is more cut-and-dry; these are the numbers versus we know patients and they have this behavior or this type of outcome. --- Professional Society Member #10

4.5 Professional Society Support of Evidence-Based Recommendations and Practice

The section below accomplishes Aim 1 of the study: Describe the role primary care professional societies play in developing and/or disseminating evidence-based reports and recommendations.

Professional societies can play several roles (disseminator, liaison, developer, and/or facilitator) in the promotion of evidence-based recommendations and practice.

For some societies, the role is that of disseminator, sharing information through:

- Email and other electronic tools
- Journals and newsletters

- Statements, bulletins, committee opinions, practice advice, guidelines, and recommendations
- Meetings and conferences
- Continuing education and training programs.

Our official journals always have articles that relate to evidence-based practice. --- Professional Society Leader #2

Our role is mostly as a disseminator. We do it through email, our website, regional meetings, and our yearly convention. --- Professional Society Leader #5

I don't think there's a document today that comes out [of the professional society], certainly from the practice division, that doesn't have evidence-based written on it and basically we live by it in terms of our recommendations. --- Professional Society Leader #6

[The professional society] is extremely supportive of the principles of epidemiological and evidence-based outcomes and practice. We incorporate it significantly into our continuing medical education programs. It's incorporated very heavily into our continuous certification processes that require competencies in reporting outcomes. We've stretched it a little bit to include patient registries, to look at patient safety and outcomes as well. So it's an integral part of our planning and our educational processes. --- Professional Society Leader #10

We carry that role out through document production (protocols, guidelines, checklists) and educational venues, first at our annual clinical meeting and through district meetings we conduct around the country. When putting forth a didactic course for our members, they hear the evidence our recommendations are based on. --- Professional Society Leader #13

We offer continuing medical education and we coined the term evidence-based CME to differentiate that which was based on expert opinion or consensus panel versus that for which there was a research-based infrastructure. --- Professional Society Leader #15

Our guidelines are published in [our journal] and are freely accessible to all interested parties whether or not they are a member or subscriber. They are also available electronically on our website and we recently developed an app for smartphones in which

one can access our evidence-based guidelines. We also have other products, such as our electronic decision-support tool, but this is a members' only benefit that offers graded recommendations for a variety of medical conditions and is designed to be accessed at the point-of-care to support decision-making. --- Professional Society Leader #16

Many professional societies take on a liaison role, appointing members to serve on external scientific panels that develop evidence-based findings and recommendations, and/or liaising with these external panels.

We have representatives that sit on the National Quality Forum and we have representatives, upon request, appointed to the U.S. Preventive Services Task Force. --- Professional Society Leader #13

So we have, for example, in the past, had an organizational liaison to the National Heart, Lung, and Blood Institute's High Blood Pressure Education Program and the Cholesterol Education Program. It's now been collapsed into the Cardiovascular Risk Coordinating Committee. As you probably well know, they have their own guidelines. We have a similar arraignment with the NIDDK and CDC for the Diabetes Education Program. We also work with the CDC Advisory Committee on Immunization Practices and have a very long heritage with the U.S. Preventive Services Task Force. We nominate members to the Task Force and I'm happy to say that one our national leaders was recently appointed. --- Professional Society Leader #17

Some of the professional societies take on a more direct role by developing their own evidence-based recommendations or measures, often in collaboration with other professional societies.

We have a consortium that brought together all specialties and 13 different provider groups (including nursing, podiatry, etc.). We developed quality performance measures, and the main point of that work is to determine what the best evidence tells us should be occurring for patients with particular conditions. --- Professional Society Leader #14

We have a commission that empanels guideline groups to develop clinical policies. We also work with other professional societies on the development of evidence-based clinical practice guidelines. --- Professional Society Leader #17

Several professional societies facilitate evidence-based practice through their divisions and special initiatives.

There are times when our role in promoting evidence-based recommendations extends to legislative advocacy, either at the national, state, or local level, depending on the issue. Clearly, one of the shining stars [for the professional society] has been their leadership role in tobacco cessation. They have been credited with being instrumental in turning the nation around in terms of getting smoke-free environments and setting the stage for the tobacco settlements. --- Professional Society Leader #7

We promote evidence-based practice in many ways. Specifically, we're very interested in promoting patient-centered medical homes. There's a definite component of this that requires evidence-based guidelines, so that's been a big piece of our promotion effort. --- Professional Society Leader #8

Additionally, three of the professional societies in this study have partnered with over 50 other societies as part of the *Choosing Wisely*® initiative, which shares evidence-based recommendations to spur conversations between health care providers and patients about what is appropriate and necessary treatment (*Choosing Wisely*®, 2014).

4.6 Awareness, Knowledge, Attitudes, and Beliefs about Organizations and Their Scientific Panels

There was general awareness of scientific panels and/or their sponsoring organizations, but little in-depth knowledge about panel composition and procedures.

There was universal awareness of the U.S. Preventive Services Task Force, although many study participants were not aware of the connection between the USPSTF and the Agency for Healthcare Research and Quality. There was also broad awareness of NHLBI's Joint National Committee on Prevention, Detection, and Treatment of High Blood Pressure (JNC), the Cochrane Collaboration, and CDC's Advisory Committee on Immunization Practices (ACIP). There was also broad awareness of the American Cancer Society's recommendations, but not their specific collaboration with ACR and the U.S. Multisociety Task Force on Colorectal Cancer. There was

less awareness of CDC's Community Preventive Services Task Force. Many participants noted that professional societies (e.g., AAFP, ACP, ACOG, AMA, ACR, AAP, Endocrine Society, American College of Chest Physicians, American College of Cardiology) and advocacy groups (American Heart Association, American Diabetes Association) had scientific panels that generated findings and recommendations.

Despite this awareness, except for the USPSTF and a few professional societies' scientific panels (such as those convened by AAFP, ACP, and ACOG—which participated in this study), there was limited knowledge among the interviewees of panel composition and processes.

I must admit to you that I don't really pay attention to that. --- Professional Society Leader #12

The NHLBI process, I don't know exactly how JNC 8 has been done. But we've been told that it is being done in a much more evidence based approach compared to the old days where you essentially got a panel together and it wasn't real clear how they had decided what evidence to look at, how to grade the evidence, how to move from the evidence to a strength of recommendation. --- Professional Society Leader #17

I've heard of [the CDC Preventive Services Taskforce], but I don't know anything specifically... I'm familiar with the name Cochran...I've come by their stuff when looking up subjects, but I can't give you a whole lot more beyond that. --- Professional Society Member #1

Although I don't know the process in any detail with NIH and CDC, they are reputable non-biased sources of information. I know the AAFP and USPSTF very well and trust what they do. The American Cancer Society - I don't know their process very well, but it seems to be scientifically based and without bias. --- Professional Society Member #5

There was also limited knowledge of the CDP. Many respondents had never heard of the program and only 1/3 had knowledge of its panel processes or composition. See Table 8.

Table 8: Awareness and Knowledge of the NIH Consensus Development Program

Number and Percent of Respondents with Awareness and Knowledge of CDP			
	Leaders n=18	Members n=16	All* n=34
Never Heard of the CDP	7 (39%)	6 (38%)	13 (38%)
Heard of the CDP, but Had No Knowledge	5 (28%)	5 (31%)	10 (29%)
Heard of the CDP, and Had Knowledge	6 (33%)	5 (31%)	11 (32%)

*Totals do not equal 100% due to rounding

Given the recent IOM report, *Clinical Practice Guidelines We Can Trust*, this study chose to ask leaders and members about why they would trust scientific panels. Responses were largely shaped by views regarding panel composition, managing conflicts of interest, and methodological rigor.

Conflicts of interest (COI) impacted panel trust, but there were perceived gradations of COI and disagreement on whether conflicted, but knowledgeable experts should serve on panels.

When discussing the composition of scientific panels, some respondents reported having the most trust in scientific panels that were comprised only of members with no conflicts of interest. Participants expressed concern that panel members with financial ties to medications or procedures under consideration, or who had published on the topic, could be unduly influenced by secondary interests.

I think people who have potential conflicts are not, in general, the best individuals to be part of a panel that's producing a document or recommendation. While those individuals should not sit on the panel, there is opportunity oftentimes for them to testify before the panel and for the panel to evaluate and interpret that information. --- Professional Society Leader #13

I would think that for someone who extensively writes on a topic or publishes, it's hard not to give the most weight to your own beliefs and work. --- Professional Society Member #5

Intellectual and financial conflicts of interest are really, really hard to ignore. People can be super and have the best of intentions, but I think it's hard to get away from those conflicts—there're just too important to people in their careers and their lives. --- Professional Society Member #8

There was also some unease with recommendations developed by clinical subspecialists, who were thought to have a greater financial stake in certain recommendations than primary care providers. Furthermore, some believed that the clinical orientation of subspecialists could influence their analysis of research.

If their membership is all very deeply involved in doing Procedure A, and they are developing a guideline on Procedure A, it's going to be a natural instinct—regardless of the evidence—to make a judgment call that it's okay to do Procedure A because you're going to see more benefits than harms. --- Professional Society Leader #1

I'm going to be very frank. When the cardiologists came out saying one in two Americans need to be on statins, the recommendation left me very skeptical. One of the first questions that comes to my mind is—why are they making this recommendation? This is going to make a lot more people have to see cardiologists for managing their care. --- Professional Society Leader #7

I have seen it over and over again. When you get a panel of like-minded specialists together, they'll quibble over ultrasound versus X-ray, or they'll quibble about one surgical approach versus another, but they'll never sit back and ask the basic question, "Should we be doing this at all?" --- Professional Society Member #12

For panels that focus on preventive health care services, such as the USPSTF, some respondents argued that primary care clinicians, not subspecialists, are the best or most appropriate experts to be at the table.

The focus [of the USPSTF] is on primary care preventive services, so my personal opinion is that the members, who are very well versed in the topics at hand, can really speak to the recommendation being discussed at the time. It's a pretty robust, diverse panel and I don't see any gaps there. --- Professional Society Leader #5

An oncologist gives you almost no expertise in cancer screening. As a matter of fact they might make it more difficult for you to understand the concepts of cancer screening. A lot of people think that if you're a clinical specialist [versus a generalist] that makes you more of an expert, but that's not true at all. What makes you more of an expert is understanding something about the clinical content you're making a recommendation about. So for example, oncologists don't do cancer screening; they do cancer treatment. So they're not going to be useful panel members for cancer screening. Primary care physicians do cancer screenings so they would be much more useful panel members as such for the clinical content. --- Professional Society Member #13

However, others mentioned that clinical subspecialists were often considered vital members of scientific panels.

Members of our House of Delegates routinely criticize the U.S. Preventive Services Task Force for not having [subspecialist] experts at the table. They would see the Task Force as being too controlled by methodologists and would say, "How in the world can the U.S. Preventive Services Task Force opine on breast cancer if there is not a breast cancer surgeon on the Task Force?" --- Professional Society Leader #9

The United States Preventive Services Task Force is made up mostly of primary care physicians. The major drawback there is they're not seeing consistently the same high volume of patients with the same type of disease, like [members of the] American Cancer Society panels, which are geared more towards cancer. So I tend to think a little bit less of the United States Preventive Services Task Force than I would of an actively practicing institution or a society that has more of a direct focus. --- Professional Society Member #10

Some respondents noted that regardless of clinical orientation, all panelists or sponsoring organizations come to the table with biases of some kind.

It's always been amazing to me that the decisions an organization may make in terms of recommendations often parallel the best interest of their members. We're a membership organization...all of these organizations represent members, so obviously they have an interest in doing what's good for their fellowship. I'm sure all of these organizations

battle, like we battle, with not doing harm to their members and at the same time doing the right thing by patient care. --- Professional Society Leader #6

Everybody knows that every medical society has some fur in the fight. They're not disbelieved, but they're looked at with more of a degree of skepticism. Everybody knows that there is a stakeholder position buried in that. We're a representative organization for our members. Our job is to advocate for and to advance them. My positions are going to be influenced by that. I'm not going to do anything wrong, but I'm going to be shaded in my recommendations about what's good for my physicians. --- Professional Society Leader #10

You hope that experts can look at this in a fair and balanced way and not let inherent bias push them in one direction or another. The problem is a lot of times you don't even realize you're biased. People with a clinical background—they're very biased too. A lot of times they're biased by their last case: "Well, I tried this medicine on that person or I did this procedure on somebody and it didn't come out well; therefore, the procedure is no good. --- Professional Society Member #14

Some respondents were accepting of panelists with conflicts of interest, especially those with intellectual conflicts, because they were deemed to be the most informed experts to make clinical recommendations.

I have yet to be on a committee where the [published] experts did not have a very good point that led to important changes in the guideline recommendation because they are the experts. Let's say you're an expert in cooking one specific dish. If you're going to have people over, you're not going to cook something that you may not know at all. If it's an important dinner, you'll go with something that you're very well aware of and that has its benefits. --- Professional Society Leader #1

If they've published [on the topic under consideration], that gives the panel report more weight. --- Professional Society Leader #12

In general, I personally would prefer to have people that know the topic very well and that means that they would have done work in that area and would have some publications. I would be careful about someone that may have sort of an extreme point of view, such as might be expressed in a controversial editorial or something like that. But

an editorial alone wouldn't necessarily be a reason to exclude someone. --- Professional Society Member #2

Several respondents thought the most effective panels were those with a balance of conflicted and non-conflicted members.

I think it's useful to have some experts that might have some conflicts of interest as long as they don't dominate the panel. And it's one thing to be at a medical school and have funding from certain industries and be part of a panel. It's another thing to be an employee of the industry itself. I have a little more problem if I think if it's actual industry representatives on the panel as opposed to researchers who may have had support from industry. --- Professional Society Member #7

I would have more confidence in the recommendations if there was a good mix. Certainly people that have done a lot of research in the field can bring a lot to a panel. But they may not have the practical experience to say how this is really translated in a clinical setting. We need to know that there are also some generalists or at least some practicing clinicians that bring practicality and relevance to the recommendations. --- Professional Society Member #11

Some were concerned that generalists on a panel might defer to published experts in the field. To ensure these experts did not dominate panel discussions or unduly influence decision-making, one interviewee suggested having a strong panel chair.

The chair plays an important role because, one of the big issues is, [published] experts can dominate the committee since they are so comfortable with the topic. But, you don't want just the expert talking—you need to hear from other folks as well. So that's the role of the chair, to make sure that experts are conveying their points and important concerns, but they don't end up dominating the group. --- Professional Society Leader #1

There was support for panel diversity, but respondents noted caution and caveats when considering lay persons as panelists.

Respondents wanted panel diversity, which could be accomplished in different ways. Some supported panelists from multiple organizations as compared to panelists from a single association.

So single specialty group recommendations, for me, immediately feel less free of bias. I'm sure they try to eliminate all the bias, but as a consumer of those recommendations I feel more comfortable when it's not coming from a single association. --- Professional Society Leader #7

It's always more powerful if multiple organizations get together and make a recommendation. If you can get all those people to agree on what should be done, that would be a pretty good recommendation. Then physicians don't have to struggle with different ones. I feel like CDC has made good recommendations in the past and they've partnered with organizations I trust—it absolutely enhances credibility. --- Professional Society Member #5

There was also support for panelists to reflect multiple disciplines (e.g., medicine, nursing, allied health fields, research methodology), to include clinical generalists and subspecialists, and to maintain diversity in geographic location (e.g., urban, rural), sex, race, and other attributes. Within medicine, diversity also meant including more Doctors of Osteopathic Medicine (D.O.s), not just different types of allopathic physicians.

I would say [our needs are] mostly met, but I'd like nurses and other professions to be represented on more panels...I would like to admonish [panels] and ask them to include other health care providers (P.A.s, physical therapists, occupational therapists) who team treat patients. And then also have a patient advocate. --- Professional Society Leader #2

I would like to see a panel involving people that have an appropriate balance of perspectives. So, geographic balance, specialty input, and I would be paying attention to race, ethnicity, and gender. --- Professional Society Leader #7

If you look at a 20-physician panel, there's often not a single D.O. on it. We've got people that are teaching at every level of every specialty and I think [panels] can do a better job seeking them out. --- Professional Society Leader #10

Generalists add a lot to the group, whereas those that are experts [in their subspecialty] add their own unique attributes. So I think there's a role for both, and I think balancing that is a really good way to go about creating a guideline. --- Professional Society Member #6

I think a mixture is good. When you get too highly specialized you can't see the forest for the trees and things are just really different if you are a specialist. They don't consider the difference in approach from someone in primary care who has a long-term relationship with a patient. You have a very different patient-provider relationship when you're a specialist, seeing from a consulting standpoint, and when you're in primary care, taking care of their mother when she's dying and taking care of their babies when they're born. You really have more of a personal relationship with them. --- Professional Society Member #15

Regardless of clinical focus, many reported a preference for panelists with clinical experience because they share the practical perspective of those who are asked to implement panel recommendations.

I want somebody who has a lot of clinical experience who can practically say, "Hey, you know, that's a good idea. But if we recommend this, we're going to add \$100,000 to the patient's hospitalization." --- Professional Society Leader #12

I'll admit my bias. I have a world of respect for methodologists, but I prefer the experts who actually deal with patients because I find oftentimes a big disconnect from people who are say epidemiologists or experts in their own right, but don't see patients and don't have that practical bent of mind or experience when they're making recommendations. --- Professional Society Member #4

[It's important to have] someone able to say, "Okay—well that's all well and fine, but that just doesn't happen in primary care. There's no point going there." --- Professional Society Member #15

There were differing views on including lay persons on scientific panels.

They'd have to be pretty sophisticated or they'll just be lost. But, there are groups of very sophisticated lay people who bring interesting approaches and thoughts. Often they would say, "We're not even considering the right questions because we're not

considering the questions that are important to patients.” --- Professional Society Leader #9

I do think there is value in having one or more people that can represent the patient’s perspective. It can be a little tricky because sometimes patient advocacy organizations don’t understand evidence-based medicine and sometimes won’t even listen to evidence if it goes against their prior beliefs about what should be done. I think the patient or consumer organizations are best if they’re folks that understand a little bit about evidence-based medicine. --- Professional Society Member #2

I think having a layperson is a particularly good idea if you’ve got broad topics, very common conditions like asthma or COPD. A lot of what goes into recommendations has to do with patient education, knowing what the patient’s needs are and what they’re willing to do. I think that having non-clinicians brings a further layer of richness to that. If it’s a surgical kind of recommendation, maybe not. It really depends on whether it’s a technical skill versus a broad recommendation. --- Professional Society Member #11

Some patient advocates want something done at all costs regardless of the evidence. --- Professional Society Member #12

There was support for internal and external reviews, but some concern about asking the general public for comments.

Respondents also described the benefits of recommendation reviews (both internal and external to the sponsoring organization) to evaluate the panel’s characterization of the evidence and recommendation rationale.

I think both an internal and external review are good. --- Professional Society Member #6

I kind of like an external review, because those are the people who are really taking the information and putting it into practice and deciding whether or not it’s going to fly in the real world. --- Professional Society Member #10

A handful of respondents discussed the risk or questioned the value of an external review, especially one that involves the general public.

I want my recommendations to be scientifically-based and not necessarily emotionally-based. When you ask to cue the public, it's going to be a rare public citizen that really analyzes the science of it. --- Professional Society Member #5

I like both internal and external review. I think there's a risk with public comment—that it can be so negative or so threatening that it can be intimidating or scary to guideline committees. But, it's probably good to have both. --- Professional Society Member #8

Clinicians often felt overwhelmed by information, but electronic support systems lessen the burden.

I think what's happened with some of these guidelines is your primary care provider is at a total loss about what they're supposed to be doing. They now know what they're not supposed to be doing, but they don't know what they're supposed to be doing anymore. --- Professional Society Member #3

It's pretty overwhelming. It's hard for a physician to keep up. --- Professional Society Member #6

Where I am, we're completely electronically run, and I think that's really helpful. We have a lot of built-in reminders and you can check [for recommendations] very easily in our system. I work for a big organization and we're constantly being updated. When recommendations change, we're notified by email and that helps a great deal. I imagine it would be more difficult if you were in private practice or in a really small group that didn't have an organized system with that sort of back up. --- Professional Society Member #9

Honestly, medical literature turns over so much now that it's almost impossible for anybody to keep up, even people who are expert in the field. --- Professional Society Member #14

It's not possible to read through the hundreds or thousands of studies that come out every month and also to do the deeper analysis of the study - to whom they apply and whether they've been validated. I find it intimidating and overwhelming. --- Professional Society Member #16

The National Guideline Clearinghouse (NCG) has the potential to support providers, but the service needs improvement.

The mission of the NGC is to “provide physicians and other health professionals, health care providers, health plans, integrated delivery systems, purchasers, and others an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation, and use” (NGC, 2014). However, some respondents noted that the inclusion criteria for the NGC needed strengthening.

There is a move to strengthen the criteria for being [listed in the NGC], to be more transparent and more evidence-based. --- Professional Society Leader #17

It's a huge problem. There are too many guidelines [in the NGC], there are too many bad ones, and at times they conflict. For the Guideline Clearinghouse right now, you have to have the equivalent, in human terms, of a pulse to get on there. I think the Institute of Medicine's report that came out recently is going to drive them to elevate the bar. It's maintained at AHRQ, which ought to have higher standards. --- Professional Society Member #12

Evidence-based recommendations can affect professional practice and satisfaction, but providers believe there is often latitude within recommendations to incorporate clinical expertise and patient factors.

Respondents reported that panel recommendations affected professional practice and satisfaction—sometimes enhancing them and at other times serving as an impediment.

I know that there are some physicians that feel [guidelines] impede [professional practice] by bringing it to cookbook medicine, but I think there's so many ways to be artistic in medicine that guidelines only enhance it... We know that evidence-based protocols enhance patient safety because you don't forget things. I get a few complaints from the older physicians that never had to follow protocols before. I think the majority of physicians really appreciate it. It makes them remember things that they need to do. It actually makes their life easier. --- Professional Society Member #5

It really depends on how a physician takes that information and uses it to the best advantage of his or her patients. I think that there are physicians that feel that a guideline is cookbook medicine, but I hear less of that now. --- Professional Society Member #6

It's so dependent upon the particular issue. I think in general clinical recommendations improve the quality of practice, but, it could interfere with a physician-patient relationship. So from that perspective, it could impede the practice of medicine, but the quality of that practice is probably improved by clinical recommendations. ---

Professional Society Member #7

I would say that [guidelines] do enhance practice by summarizing large amounts of data. Do they make it easier? I would say no. I think in some ways they make it potentially harder. There's a lot of guidelines, making it confusing, which might reduce satisfaction. And, there's another part to it. There's an article, oh gosh, like 12 years ago in JAMA that showed if you did everything recommended in guidelines, it would take like four hours for a patient visit. So, in that way, I think it makes practice harder. --- Professional Society Member #8

I think it enhances practice and satisfaction because you're not struggling on a daily basis to figure out what to do. --- Professional Society Member #11

If they're well-done clinical guidelines, I think they're very useful because it gives you an objective summary of the current state of the evidence which is very hard to stay up on as a clinician. However, if a guideline is done poorly and all of a sudden that becomes the standard of practice and now the standard of practice is a non-evidence-based, somewhat expensive, potentially harmful intervention, and you're held to that standard, now it's become a hindrance. --- Professional Society Member #12

*I think some providers feel that with too many recommendations medicine becomes cookbook and they like the freedom to think and apply the stuff they know. But there's still so many nuances that, if you consider the study population and the different risk groups, there's still a lot of room for interpretation. As to whether that affects satisfaction, I think that it gives people more confidence; feeling like what they're doing has been validated, and the confidence increases satisfaction. But, at the same time, people are concerned that it's taking away some of their autonomy, so it may be a little bit of a balancing act. --
- Professional Society Member #16*

To hone in on aspects of professional practice, study participants were asked if panel recommendations influenced clinician autonomy.

You always have the tension of "cookbook" medicine. In our country, we're being raised where the individual is supreme. That's why we moved away from the oppression we had with England. We've always worshipped the individual, which is somewhat in conflict with epidemiologically-based medicine. When I walk into a patient room and shut the door, it is me and that patient. There's always that conflict between population and individual. I don't see it ever going away, because as a physician, I have a commitment to try to do everything that's deemed appropriate for my patient. --- Professional Society Leader #10

No, and I say that because at the end of the day—at this point anyway—you're free to accept them or not. I think [my professional society] does a particularly good job of stressing that their recommendations are not the standard of care and that if you don't follow them, you're not going to be subject to a lawsuit. They're there just as a guide, as a help, but they certainly don't cover every scenario. --- Professional Society Member #4

I think they do in a good way. Professional autonomy allows you to be a bad doc. "Sure, I want to protect my autonomy to do out-of-date, harmful and ineffective practice!" That's professional autonomy. To the extent you want to protect that, then don't do anything. But guidelines, if done properly, keep you current. There are always allowances for individual considerations in guidelines and almost every guideline starts with that caveat. --- Professional Society Member #12

I think it actually makes you a lot more autonomous. In the past, some primary care docs might not have known about screening women for breast cancer. Before the age of guidelines, a physician might have said, "Oh, I don't know- let me go ask my local oncologist." With these guidelines, it allows primary care physicians to look at things themselves and make their own decisions based on the evidence...A lot of physicians say, "Oh well, it's telling me I have to do this and I can't do this and that's stepping on my autonomy." That's not what guidelines do at all. There's no guideline that says you always have to do this or you never should do that. The guideline always says in general you should do this, but if there's something about that particular individual that makes them different from the general population then you might care for them differently. That's an issue of interpretation so physicians who think that guidelines are impeding their autonomy don't understand guidelines. --- Professional Society Member #13

Of course recommendations affect autonomy. Nobody likes to say you're supposed to do it this way. Because when you're looking at population-based recommendations it really is not 100% applicable to the patient sitting in front of you. You have all these other things that are intervening. People say these are guidelines, they're not written in stone, but if you don't follow those guidelines or you're not following enough people with those guidelines then they say that you're not practicing standard of care. So people get infuriated by these things. Sometimes it's legit and sometimes it's just a lame excuse for really not doing the job they should be doing. But you can always fall back on that as an excuse. I think experts, clinicians, and public health people have to come together to come up with something that's reasonable and then have enough latitude within that to use common sense. --- Professional Society Member #14

Professional tensions were noted, most frequently between academicians involved in developing recommendations and the rank and file clinicians involved in implementing them.

Definitely, I would say there is tension. Some of the guideline writing bodies craft recommendations that are especially based on their personal experience, their own perspectives, and the limitations thereof. Some of the guidelines are written with the belief that everybody has an academic medical center at their disposal, and has this perfect patient population to try and apply the guidelines to. I think that there's an increasing understanding that's not the best way to write a guideline. And especially with randomized controlled trials, I would say that's an area where a lot of physicians look with skepticism, because they weed out all the comorbidities and then you don't have any real patients. --- Professional Society Member #6

When patients are enrolled in a study, obviously there are drop outs, but the patients that remain are compliant, they have a vested interest, whether it's for the drug, for their honorarium, or even just their interest in the study. The problem is that sometimes boiling down those recommendations and then telling physicians, PAs, NPs, whatever, to put them into practice is hard because the patients we see on a regular basis aren't like the patients being followed in the study. Our patients have other comorbidities, but in academia and research it's more of a controlled environment. For us it's more of a free-for-all. While we realize these might be good recommendations, they may not be realistic for most. --- Professional Society Member #10

Oh, absolutely, absolutely [there's tension]. People who are on the front-line, seeing patients, trying to pay the bills, trying to keep the lights on, trying to keep their patients alive, recognize the realities and when some recommendations come out, they just seem sort of esoteric and don't really fit the realities of practice. I hear people say, and I have felt this when I was pretty disconnected from academic sorts of practices, that it seems like a sort of mandate from the mount. --- Professional Society Member #15

One respondent described tension between administrators and rank and file clinicians.

There's a lot of tension there because physicians are in a tough spot. We've got a clinical integration program here where we do measurements and reimburse physicians for the quality of the results that they get. When patients are sicker, administrators don't always understand how hard it is to implement these things. I believe as a physician, who's also an administrator, it's important for me to keep my hand in clinical practice for that credibility. Those that have stepped out of clinical practice can lose that credibility pretty quickly. --- Professional Society Member #6

One participant noted a tension between academics and specialists.

I think there's more tension between the specialists and the academics who are making the recommendations, because often the recommendations that I've seen have fallen more in line with what the primary care doctors are seeing. It's the specialists who, just by the very sake of being specialists, get a skewed view of things, and so I see much more tension there—at least with the recent PSA and mammography recommendations that have come out. --- Professional Society Member #9

Others identified a tension between generalists and specialists.

In our House of Delegates there was quite a debate about the urology guideline. The primary care physicians were the ones that said, "This recommendation came from the U.S. Preventive Services Task Force and we think this is a very credible organization and a credible recommendation." The urologists were fighting this on the House floor saying, "We didn't like the panel; we don't think they were expert enough. Who are these people anyway?" --- Professional Society Leader #7

The section below accomplishes Aim 2 of the study: Determine if the needs of primary care providers and their professional societies for evidence-based reports and recommendations are being met.

Views varied on whether scientific panels were meeting the needs of professional societies for evidence-based recommendations.

When asked if scientific panels were meeting the needs of professional societies and their members, some participants reported a qualified yes.

I think generally, for many of the professional societies, yes. But the burden is on us to make sure that these recommendations are coming from a valid source, that they are evidence-based, and that they're trustworthy enough that we feel confident in spreading the word. --- Professional Society Leader #4

I think in general the answer to that is yes. I mean there are always other things that we might want to have looked at, but I think overall we've been fairly pleased. --- Professional Society Leader #13

Some respondents noted that when external scientific panels left gaps, their own professional societies would develop recommendations.

Yes - I think in most areas [our needs are met]. When we see an unmet need, where our members express consternation in not knowing which recommendations are the best or if all of the recommendations that are out there appear to come from conflicted constituencies, then we tend to pull things together to make our own recommendations. --- Professional Society Leader #15

Well I think that the USPSTF is doing a great job. And I would say, when coupled with the guidelines that we produce ourselves, we're meeting the needs of our members. --- Professional Society Leader #16

Other respondents voiced frustration with available guidelines.

There's inconsistency. There's stakeholder conflicts that are involved in it, and guidelines frequently are not followed up well enough. A guideline will be issued to a great degree of publicity, and then it kind of goes away and nobody hears anything further about it until the next crisis. --- Professional Society Leader #10

It's difficult when a panel does not rate the evidence or their recommendations. It's difficult when the guideline is not clear in the link between the process of care and the

outcome. It's difficult when the guideline is not accompanied by an implementation plan. --- Professional Society Leader #14

I think some guidelines have been very helpful and influential in practice. I think the problem is that there are so many of them that it makes it difficult for busy practitioners to keep up with them and to know which ones to pay attention to. --- Professional Society Member #2

4.7 Provider Utilization of Scientific Panel Reports and Recommendations

Clinicians tried to follow panel recommendations, with the caveat that there were always exceptions for patients with unusual circumstances or characteristics.

I am one of those physicians that rely heavily on [clinical guidelines]. I call myself a guideline girl and whenever the five of us in my practice are trying to make individual decisions, we always rely on them heavily. --- Professional Society Member #5

I try to follow panel recommendations. If it's from a reliable source, I would rarely not follow it because I disagree. It would be because the patient doesn't fit into that guideline. An example is the CT scan for lung cancer. The people who should be screened are patients that are well enough to benefit from therapy. If they've got heart failure and so forth, they're probably not going to be able to benefit from having part of their lung removed. They might die from that surgery. To follow a recommendation, the patient must benefit. --- Professional Society Member #8

The right thing can change from person to person. So that's where I think being an expert clinician comes into play. Where you balance these recommendations against the patient in front of you knowing the limitations they might have, to make the best decisions for that patient, using an evidence base to support it. --- Professional Society Member #14

Clinicians resolve the heterogeneity of recommendations in different ways and often share decision-making with their patients.

You really have to go back and make it a doctor-patient relationship. Instead of me telling you what to do, it's me educating you in the differences and us reaching the decision together. --- Professional Society Leader #10

All the work is done on electronic medical records, so you are prompted to check for certain things given a certain situation, and prompted on which actions to take. Usually the stuff there is straightforward. I tend to look up things that are not typical. ---

Professional Society Member #1

We saw a lot of [heterogeneity] with mammography recommendations: the U.S. Preventive Services Task Force, [our professional society], the American Cancer Society, and the American College of Radiology. So when I do see [differences], I usually will look towards [my professional society] then look at those other recommendations and try to find out why there's a difference. Sometimes I can see why and explain that to my patients, and other times there is frustration. --- Professional Society Member #5

Well, I have to say that in my own mind I'm very aware of the harms that can result from excessive testing, excessive use of medications, and things. So I tend to err on the side of less is more in terms of medical care. That would probably be a bias that I bring. When I see conflicting pieces of information and really feel stumped about it, I go to where I believe the best information comes from which would be the U.S. Preventive Services Task Force or [my professional society]. --- Professional Society Member #6

The way that I dealt with [mammography recommendations] was talk with my 40 to 50 year olds about it. We talk about the risks and the benefits. We talk about their family history, their concerns. And then we decide what they want to do. I try to inform them and let them be involved in making that decision because the evidence is somewhat conflicting. So for things like that, I tend to try and involve the patient more. If it's something where I feel there's less conflict, I'm more likely to decide what I'm going to follow, like pap smears, and how frequently to do them. --- Professional Society Member #9

I would go online and I'd do some research and I'd look at reputable websites - Mayo Clinic, Cleveland Clinic, John Hopkins; I'd see what they say. I'd talk to peers in my field or talk to peers who are specialists. --- Professional Society Member #10

I think in those instances it probably is a systems issue because people mostly practice in systems now, which adopt one group's recommendations over another's for various reasons. For instance, if you practice in Cigna in Arizona, they have their own set of recommendations that seem to be a bit of a mix between the U.S. Preventive Services

Task Force and some accommodation to some really outspoken specialty groups who disagree with the USPSTF. --- Professional Society Member #12

I think that everybody looks at it with their own bias. So if you're looking for an answer it's sort of like shopping for a consult. If you want a specific thing you can probably go to a number of people until you get the answer you want and that's the one you believe. And then you can verify that because so and so said it. --- Professional Society Member #14

Typically I, however naïvely, assume that the organizations with the least agenda are perhaps the more reliable and so often for a lot of the preventive screening recommendations I will turn to the United States Preventive Services Task Force. I tend to prefer that over individual societies like the American Neurologic Association because they have less of a vested interest in a particular area. However, I do take into consideration some of the deeper analysis that is done by these societies; the USPSTF gives a very blanket recommendation. Some of these societies have looked at subpopulations, whether its minority groups or certain high risk groups, and they give recommendations that the USPSTF does not address. So I try to look at it, weigh the evidence, see who's involved and what seems reasonable and unbiased. --- Professional Society Member #16

Contextual factors (e.g., access to facilities, regional practices, patient beliefs, enabling resources, perceived need, provider preferences) impacted the utilization of evidence-based recommendations.

Although the health care system did not influence provider support for recommendations, it did influence patient access to recommended services, especially among rural populations.

We are the primary care providers of health care in rural and remote communities, so access to the things that we recommend are substantial considerations. For example, if you live 200 miles from nothing, a colonoscopy can be kind of hard to get. --- Professional Society Leader #15

We're a rural state. I'm seeing patients in a town two hours away this afternoon and there are certainly patients who cannot access what I recommend or what the consensus panel recommends. --- Professional Society Member #4

Some respondents said that access to providers, equipment, and health facilities was not a barrier in their work because of connections to large, university-based, multispecialty practices or the U.S. Veterans Health Administration.

Many participants observed that the external environment, particularly regional practices and controversial recommendations (either socially or scientifically) impacted providers.

If it's [scientifically] controversial, to me that's a warning that there may be different points of view. It would push me to look harder regarding why it's controversial. Is it because the data is not good? Is it because the findings are a threat to certain people's livelihood? I'd do more fishing. --- Professional Society Member #1

Any issue around abortion would be a topic that we would probably stay away from. --- Professional Society Member #3

You kind of practice the way people in that region practice, and if you're not doing it the way they're doing it, they might judge you to be practicing poor medicine. And so you adapt, and yet it's not necessarily appropriate. We have an excessive amount of regional variation. --- Professional Society Member #6

What's common in our geographic area is definitely a big influence on our standard of care...If it's controversial, [clinicians in my area] are afraid of the liability. --- Professional Society Member #10

Part of its buy-in for patients. If patients are reading up on it and it's controversial, that can cause a problem. I might be more leery to do it. --- Professional Society Member #9

Many clinicians stated that if a guideline was trustworthy, they would still recommend it regardless of any surrounding controversy.

If it was a reputable entity and a scientifically based, good guideline I would still make the recommendation. --- Professional Society Member #5

Predisposing characteristics also have an important impact on utilization of health recommendations. For many clinicians, patient knowledge, beliefs, and preferences did not

greatly influence whether or not a service was recommended, but these characteristics did influence patient-provider discussion, shared decision-making, and consideration of alternatives.

[Patient knowledge, attitudes, and preferences] would not change my recommendations. I wouldn't forgo telling someone to stop smoking just because I don't think they'll do it. --- Professional Society Member #1

Obviously it's a patient's choice what kind of treatment to accept, but that would not change our algorithm. We would just move the patient further down the algorithm if they declined a recommended therapy. --- Professional Society Member #3

I recite [recommendations] to patients whether they'd like to hear it or not. They can choose not to do it, but they should have the education and know that's the recommendation. --- Professional Society Member #5

[Patient knowledge, attitudes, and preferences] affect my ability to implement a recommendation, but I really like to give patients the choice. I make a recommendation based on what I think is the very best thing in that situation, then let them apply their own values to make the decision about whether to follow through. --- Professional Society Member #6

[Patient knowledge, attitudes, and preferences] definitely come into play and should. It's a tricky one; however, because somebody comes in and they really want something that's totally unindicated, harmful, and useless. It's a discussion that needs to occur. --- Professional Society Member #12

If the patient doesn't buy into it, they're not going to do it. Colon cancer screening is a very good example since many patients are reluctant to be invaded in that way. We encourage them to do it and try to find and facilitate ways for them to get what they need. If they won't take the gold standard recommendation, we encourage them to do the next best thing. We try to modulate patient compliance to provide the best possible care for patients on an individual basis. --- Professional Society Leader #15

Provider preferences were cited by some study participants as influential in their communication about recommendations to patients.

I'd like to think all my clinical work is based on best evidence, not my own preferences, but I realize it isn't. I like to minimize my own personal preferences as much as possible, but there's a certain level of familiarity in certain things that drives a lot of decisions. ---

Professional Society Member #1

[As a provider] I have preferences, but they don't go outside the recommendations. I think if reputable organizations said this, that, or that, and they are equal in all senses, then I would probably share my preference with the patient on which of the three I would do. --- Professional Society Member #5

There's no question. If I have had a particular treatment or test in my own life, I play out my discussion [with patients] slightly differently. --- Professional Society Member #6

Most providers reported that a patient's enabling resources, such as health insurance, were an important factor influencing utilization of health services.

Yes, absolutely [coverage influences utilization]. Some things just aren't covered or a patient can't afford it based on what the copay is. This happens very frequently. --- Professional Society Member #4

I ran into that today, in fact, where the best view of the pancreas was going to be with an MRI to see if the person has cancer, because we're very concerned about that. But the insurance company wanted a much cheaper test, which was an ultrasound, that's far inferior. We ended up with a compromise, the CAT scan, which is still not the best view. So you end up with these battles that can go back and forth between the doctor and the insurance company. --- Professional Society Member #9

When asked if providers would discuss a recommendation for which there was no insurance coverage, all respondents acknowledged they would.

Yes, I would bring it up, but if it's not covered then I need to let my patient know that they might be on the hook for it. --- Professional Society Member #2

I would make the recommendation, whether it was covered or not. But then certainly, the patient would be informed if it was covered. I would still make that recommendation if it came from a reputable source. --- Professional Society Member #5

I wouldn't not bring it up. Sorry for the double negative. I would bring it up. I feel like that's something I have to do. And that's something I thought about over the years realizing that it's not a good thing to let that excessively influence your recommendations.
--- Professional Society Member #6

Some participants discussed how a patient's self-perception of need and a clinician's evaluation of need have impacted primary care providers and their professional societies.

We did such a wonderful job of inculcating in women the need for a yearly Pap smear when they first came out years ago. Now many women feel like if they don't get a Pap smear every year, regardless of the circumstances, that they're not being treated with the greatest respect and utmost care. [The professional society has] been working on getting that message out to our members, but it's not easy. Patients expect a Pap smear every year, and the second thing is that the physician's bottom line may be affected if women don't come in for these annual visits because they see no reason to. So it's things like this, where we wrestle with what we know and preach is good medicine, medicine that certainly is changing because our recommendations today are certainly much different than our recommendations on Pap smears 5 to 10 years ago, and our support for the interest of the members of our society. --- Professional Society Leader #6

As you know, not all providers follow immunization recommendations. So often that's why there are a lot of vaccine preventable illnesses that are occurring in the U.S. I hate to say this, but with vaccine preventable illnesses, people sometimes do not see the value of prevention. They don't see the value of immunizing because they've not seen the disease. And so I think we need to improve the provider knowledge base—they need to always be inquiring about the patient status for immunizations. --- Professional Society Leader #11

Clinicians have some influence in modifying contextual factors, but barriers remain and inhibit utilization of health care services.

Patient knowledge, yes; we can certainly influence it. Insurance coverage- only to a certain degree; you can fight and fight - so sometimes you can influence insurance coverage. Patient access, that's a tougher one, too. You know, we do our best. If a patient can't access, we would assist them in accessing it. I think it would just be more a matter of time. --- Professional Society Member #5

Some of my patients have been from the inner-city. They are Medicaid or self-pay, and so access to specialists can be a problem. I've called Catholic Charities and tried to cajole my colleagues. But there's a limit to how much you can do that. It doesn't necessarily mean you're going to be successful, but you tried your best. --- Professional Society Member #6

I do think that the insurance companies in general have learned and that they're pretty decent in terms of how they apply the science and approve a recommendation. What I run into more so has to do with just coverage in general. So if a patient has no insurance that's a challenge. I have had to sometimes try and find resources for them. I try my best to really let them know this is a strong recommendation. We need to figure out a way to do it, or else, accept the fact that we're taking that risk. --- Professional Society Member #6

If the insurance won't pay for it, my patients generally can't and so I try to find a way to work around the resources that they have. But [a workaround] is not always possible. Medication can be denied, and I've had this happen where I just cannot get it approved and it's the only thing I can use. And that's really tough, because then it's out of pocket which means it's probably not going to happen. --- Professional Society Member #9

4.8 Value Federal Government Contributes to Evidence-Based Practice

The section below accomplishes Aim 3 of the study: Describe the value that the federal government contributes to evidence-based practice.

Although there were some criticisms of specific federally-sponsored panels, the majority of respondents believed the federal government substantially contributes to evidence-based practice by facilitating the development of high quality, evidence-based reports and recommendations that guide clinician practice.

Federally-sponsored panels are valuable contributors to evidence-based practice because of their objectivity, transparency, balance, methodological rigor, and prioritization.

With the U.S. Preventative Services Task Force, for instance, we expect that the recommendations are held to a really rigorous standard. The process is highly vetted and taken very seriously. The data is reviewed very carefully. I'm not sure this is necessarily cool to say in this day and age, but the fact that it's coming from the government really

lends it some weight. You expect that the government is trying to do right by its citizens. --- Professional Society Leader #4

Well, my most direct and personal experiences are with the USPSTF, and I would say they're absolutely trustworthy, unquestionably trustworthy. I'm in the room when they listen to evidence reviews from the practice centers and they take great care in digesting the information. They ask a ton of questions, and it's a very thorough process. --- Professional Society Leader #5

I have to give the federal government a lot of credit in really trying to deal with balance and diversity, and that would be all the forms of balance that you might hope for whenever possible. So, geographic balance, specialty input, race, ethnicity, and gender. I feel like it's about as good as it can be. --- Professional Society Leader #7

People do not feel you're necessarily taking a stakeholder position. They can disagree, but they disagree intellectually, and not because they think that you're taking a stakeholder position. That's a huge advantage. --- Professional Society Leader #10

There are two biggies that [federally supported recommendation developers] bring to the table—transparency and a rigorous process. --- Professional Society Leader #14

My experience is that the federal government has done a good job of concentrating on things that are a high priority, visible, and that "make a difference." The reality is that there isn't enough money to do everything and so the federal government has to focus and prioritize what it does, and I think that a lot of very bright and responsible people have worked very hard to make sure that the right prioritization takes place. I tend to be fairly cynical when the government is concerned, but I've had enough contact with it to know they try very hard to be conscientious about that sort of thing. --- Professional Society Leader #15

The federal government tends to go out of its way to ensure that the diversity of relevant constituencies all have input on any given subject. They cast a very broad net and so the likelihood of any leveraged recommendations coming out of a federal group like that is relatively small. --- Professional Society Leader #15

If it's a panel that NIH puts together it's inherently trusted because the assumption is there's a great amount of rigor in the assembling of the data or the individuals involved.
--- Professional Society Member #7

The federal government also contributes to evidence-based practice by covering certain USPSTF recommendations (i.e., those graded A and B) through the Affordable Care Act (ODP, 2014e).

4.9 Comments and Suggestions for Federal Scientific Panels

Study participants offered many suggestions for improving federal scientific panels. These suggestions were related to panel composition and processes; the feasibility, readability, acceptability, and dissemination of evidence-based recommendations and reports; and strengthening partnerships with stakeholders. Key portions of quotes are underlined below to highlight suggestions for federally-sponsored panels.

Improving Panel Composition and Processes

You need to get rid of this variation with multiple, different panels. Honestly, if I had to pick one - I would probably go with the Task Force model—but include experts. A standing panel provides coherence of a sort - the same thinking, same guideline process and same methodology. Variation can be a big problem because of training your panel members. If you're going to have multiple panels, multiple committees—I strongly think you need to have training. If it's a single panel and you're going to be slowly graduating (a slow turnover like two or three members rotating up every year and then the new members come in) it's easier to control the training. You need to have a two or three day program where people understand evidence-based clinical practice guidelines, definitely.
--- Professional Society Leader #1

I would increase the capacity of the USPSTF. Now that it's become written into ACA there are so many issues and its processes are very meticulous; it cannot possibly address all the issues in a timely fashion so it's going to be woefully inadequate. --- Professional Society Leader #9

I was always frustrated as a pediatrician [on the USPSTF] because the sort of studies that you're looking for—to support A level evidence—are rarely going to be done for

children's issues because you would need to have a randomized controlled trial for which the findings take you out 40 or 50 years. It's just never going to be done. So I think a lot of the pediatricians on the panel have been frustrated by the marriage of the Task Force to the large randomized controlled trial. I think they have been looking at some other methodologies that are very helpful. But the question about what advice we should give on topics that don't have that level of research, or whether we should just stay away from those topics completely, is a conundrum that needs to be solved. --- Professional Society Leader #9

If you start getting into politics, then you're going to become untrustworthy. The country is so radically divided, 35% to the far right and 35% to the far left and, you know, 30% in the middle. You can't stay away from controversial issues, but as long as you keep [recommendations] purely evidential, with the emphasis on patient care and outcomes, then you'll remain respected. You may be disagreed with, but you'll be respected. --- Professional Society Leader #10

I think it would be helpful for [federally-sponsored panels] to make clear the diversity of input and the efforts that they've gone to ensure that all relevant viewpoints have been taken into account and that responsible, researched, peer reviewed sources have been consulted. Articulating the conscientiousness of process would be helpful. --- Professional Society Leader #15

We're optimistic, guardedly, that NIH Institutes are going to move forward with being in a manner similar to the CMSS and IOM recommended processes. --- Professional Society Leader #17

I know it's nice to have an event and release the recommendations right after the jury has huddled, but maybe launch a process where you have a more apparently thoughtful processing of what's been heard. --- Professional Society Leader #17

I would pay attention to the IOM standards for guidelines now and I certainly would want the consensus panels to follow that. --- Professional Society Member #2

I think there's always going to be that specialist versus non-specialist argument. I think making sure that there is a specialist on panels helps silence those critics. I think that the loudest criticisms that I heard were there weren't specialists on the panel for

mammography or PSA. But at the same time, I wouldn't want to see a panel that was just specialists by any means, so more of a balance. --- Professional Society Member #9

[The federal government] should try and build more consensus throughout the community. What I would like to see is more consensus, support or conversation from government funded groups with other organizations that make recommendations. --- Professional Society Member #10

I think in general panels should include more members at the grass roots level. It would enhance their credibility and [their recommendations] would seem more real, approachable, and applicable to their part of their world. --- Professional Society Member #15

Making Recommendations More Feasible to Implement

The American Academy of Family Physicians has a website for physicians to answer common questions and often it will have a patient handout with it, and it's embedded within my EHR. When I'm in an EHR, it's not easy for me to get out of that EHR and get into CDC's website. But, within my EHR I've got Up to Date and AAFP. So the challenge at the real level of the practicing physician is to look at how to get [recommendations] to point-of-care, apps maybe, but I don't know how many physicians within their offices are actually using a mobile tablet. --- Professional Society Leader #7

I do think apps are very applicable—put an app in place and work with the electronic health record companies for good decision support functionality. You really need to build that into the care process more so than anything. --- Professional Society Member #6

I think considering the insurance side of it is probably the most important. When making recommendations, be explicit about exceptions or you can really tie the hands of the provider. --- Professional Society Member #9

Make sure they're covered [by insurance]. Connecting the recommendations with a covered ICD9 Code would be awesome, versus me just saying, "You've got to get this screen" and then the insurance company comes back saying, "No." Have some type of preventive code for major recommendations that the insurance companies are already going along with. --- Professional Society Member #10

I would like to see new guidelines come out, and then also see the government step forward and say, “These are new guidelines and we support practitioners who implement them”—making a statement about liability. For example, the US Preventive Services Task Force, I think, offers a grade D for PSA testing. We're still doing it on a regular basis because some [panels] recommend it. If I'm getting sued and referencing the US Preventive Services Task Force, others will cite organizations with different guidelines. What I would like to see is more consensus from organizations that make recommendations. That's what I would like to see because, again, liability is always concerning to me and there's a risk to my patient's health if they don't get a test. --- Professional Society Member #10

Right now it's all procedurally based as far as remuneration. That's why it's so hard to get people to go into primary care because you're just not paid for your time. You're paid for a procedure. I talk to my patients and educate them, and I'm not paid very well for that. I think that's where the federal government can play [an important role]—start incentivizing people to do these other things. --- Professional Society Member #14

Improving Readability, Acceptability, and Dissemination

Perhaps more outreach activities. I work in a big academic institution and we tend to get this stuff filtered through to us pretty quickly because there's always somebody in our organization who's connected with these panels in some way and wants to get the word out. But, I wonder if there's a better way to do outreach for private practitioners or community based practitioners or people who work in smaller academic environments, where basically, these new recommendations may not be handed to them as readily. So, maybe outreach efforts that focus less on some of the major academic players and more on, most of the providers in the country, really community based or sort of smaller organizations. Reaching out, starting smaller, more locally/regionally, as well as nationally. --- Professional Society Leader #4

I think that if you get out of D.C. and out of Bethesda, and go get involvement in Chicago and Dallas and Kansas City and Denver, you will expand your market tremendously. Things that come out of D.C. appear to disseminate much slower than something that comes out of Stanford, or something that comes out of Washington University in St. Louis. --- Professional Society Leader #10

Sometimes the recommendations that come from the U.S. Preventive Services Task Force may be very legitimate from a statistical evidence basis. But they could use some help from a communications firm to help them communicate their recommendations in ways that are less inflammatory to the public. --- Professional Society Leader #15

When I look at some of the recommendations, with the exception of the United States Preventative Services Task Force, I don't think they're as reader friendly, generally speaking, for our members. Some of the recommendations tend to be quite long and are not as accessible to our members because of their length. --- Professional Society Leader #16

Put your recommendations in a table at the front of the manuscript. That's basically what I'm going to look at. I'm not going to read the text and that's what our members are telling us too. --- Professional Society Leader #16

One strategy that could be used by the NIH panel to make their recommendations more assessable to the general public [is to] make it accessible electronically so one could use it on a mobile device and access it at any point in time that they needed it. --- Professional Society Leader #16

If the AHRQ Guideline Clearinghouse does strengthen their criteria for entry, that'll help [with dissemination]. --- Professional Society Leader #17

Professionals have national certification exams. We do this exam and have to maintain our license so we're still proficient with things. People study for the exam, but I think if there's some type of push to make guidelines a bigger component, it might be beneficial because people will prepare specifically for them. I think when people put effort into things, they stick. --- Professional Society Member #1

There should be more of an emphasis on readability. I'm ashamed to admit it - I've been part of a group that did a lot of work and it was so wordy and so detailed that it really didn't get used that much. --- Professional Society Member #4

I think that too often the results are marketed by and large to academicians and not to practitioners in the field. Because when I talk about a recommendation or a panel, a lot of people have no idea that that's ever been done or what the report is. The results don't

always get disseminated to the people who really need to get them, because private practitioners aren't reading a lot of literature. --- Professional Society Member #4

Periodicals like OB.GYN.News and Contemporary OB-GYN—you know, people in academics look down at those because they're glossy and they're more like a magazine than like a journal. Some people think they're not very serious. But when you go talk to a private practitioner, go see what's on their desk, what's on their table. It's those things. It's not the journals. So look at the venues that people are actually reading, and it's not who's subscribing. --- Professional Society Member #4

I think it's definitely how it's presented to the public. Mammography was not presented well and that was part of the problem. If it's not presented well the media can take over and people who are celebrities can start getting equal say or greater say than the Task Force themselves. We've seen this with vaccines and autism. Really trying to take control and planning out your message beforehand is so important. I saw it happen with mammograms; I started seeing young celebrities who had breast cancer coming out saying, "Oh, this is so horrible," and I can guarantee they probably had not read the recommendations completely or the entire report and what it was based off of, and they probably didn't have expertise to read the research in the first place. So - that's a problem with all of the specialty societies - making sure that we get out there ahead of non-medically based media. --- Professional Society Member #9

The American Cancer Society has a nice little screening card and one is pink for women, and one is blue for men and they're different ages. It's a pull down card and says women at this age should have this, and you pull it down and you line it up with your age and it'll say, annual breast exam, mammogram, PAP, pelvic, at age fifty colonoscopy, routine eye exam. I think those are great and some insurance companies send that out. It helps us out a lot because I do see it increasing patient compliance because they bring it in. My time with them is limited only because patients have multiple concerns. I'm addressing their meds, their insurance, refills, you know, new complaints. So it's not just the recommendation, it's having certain tools to go along with it and I like giving those out. I like to pull stuff off-line. You know, someone says, "Why do I need a colonoscopy?" I go on the American Cancer Society website, pull it up, and say "Here you go. Here's your information. Here's why, here's why not, here's what your options are." Then they can take it home. If I feel like they didn't quite get enough information, or they said no and I

still want them to think about it, I give it to them. So the tools are useful. --- Professional Society Member #10

Do not use the term physician unless it's something that only a physician can do. --- Professional Society Member #11

Well I think that mutually agreed-upon recommendations, a consensus opinion, through task forces or conferences would be the ideal scenario. Alternatively, maybe some of the more general societies could present not only their recommendations, but set them side-by-side with recommendations by the specialist societies and list them with the pros and cons to say, "You know, the panel came up with this recommendation, but the society still recommends this for these reasons." People could see them side-by-side and understand with better transparency each of the options. --- Professional Society Member #16

Strengthening Partnerships with Stakeholders

Well, I honestly feel like [federally-sponsored panels] already have good credibility. So how do you make that better? I think what nurse practitioners would like is to be recognized that they deliver quality care and that they appreciate good guidelines or recommendations and clinical resources. So I think it's really to reach out, to target nurse practitioners as an audience member, and to maybe include them. As new recommendations are coming out, or as things are being produced or developed, I think to have a nurse practitioner on the panel or at least as an advisor or consultant would be very helpful. Most know and trust most of these panels, so it's not really a hard sell. But they do appreciate being acknowledged and having the opportunity to be involved. --- Professional Society Leader #3

Work more on building consensus among organizations to harmonize recommendations. --- Professional Society Leader #6

I think there might be [opportunity for] specific linkages with professional societies around things that are new or important for people to pay attention to. And partner on continuing professional education. It seems like as long as you've got it on your website why not give CME credit. You do a pretest and a posttest and really make sure that you've read it and that they aren't just opening up and claiming credit for it. That would be a real enhancement. --- Professional Society Leader #7

Conduct your process with the specific inclusion of people that have to disseminate whatever you produce. If we had known that you guys were doing this to start with we would have helped with the implementation. --- Professional Society Leader #8

I think that there's a lot to ask [professional societies], "How is this going to be received and how can we talk about it in a way that maximizes its positive receipt? How does this land on you and how is this going to land on your members? What are their concerns and questions going to be?" It's always helpful not to be surprised. --- Professional Society Leader #9

I think that one of the things that is very helpful is for folks to actually observe the process—describing the process doesn't usually do it. But my experience is if someone gets close to the process, participates in some way, pretty soon they're drinking the Kool-Aid. --- Professional Society Leader #9

I would just say in the spirit of promoting collaboration, we should align with the schedules of new recommendations coming out. In other words, we fully respect that those committees need to do their work without any external pressures. You know, they need to remain independent, objective, and do their work. But as organizations, can we sort of talk to each other and say, "Okay, you know, the schedule is these three guidelines will be updated in 2014, these in 2018. Can we plan now or let's try to pilot a way to rapidly spread the information? Could we be more team-like in the design of translation while in no way tampering with the credibility of the guideline development work?" --- Professional Society Leader #14

Don't know how realistic this is, but perhaps add some sense of how the guideline would be carried out in practice. I know that's difficult, right? I guess you would call it implementation, interpretation, translation examples and that's part of where we want to try to be helpful. Maybe we could bring some of that to bear, recognizing the guideline panels. [Clinicians] commit an awful lot of their time and energy; how much more can you ask them to do? Maybe it's a different expertise if you think translation. Could we be the arm that tries to supplement that work with some real world implementation translation approaches? --- Professional Society Leader #14

I think to the extent that professional organizations are involved in the creation of recommendations is always helpful, which may be participating as a panel member to

simply reviewing and commenting on draft recommendations. --- Professional Society Leader #16

Well, one I think you're already doing now, which is understanding what the specialty societies are doing and what they feel are appropriate evidence-based clinical practice guideline methods. Second would be to look to us as perhaps being able to nominate people for panels. --- Professional Society Leader #17

Get input from [professional societies] during the process and then follow up with them when the reports are ready for release. That could help with dissemination and impact. --
- Professional Society Member #2

You get this big disconnect in the recommendations that are made and the people that are on the ground practicing every day. So, if you could figure out a way to enhance that relationship—between those individuals that are creating guidelines and those that practice day-to-day—I think it would be really helpful. The problem is that physicians consider population-based guidelines just that: they're population based and don't really apply to their practice. --- Professional Society Member #3

The next step in all this is going to be harmonization so that you don't have different groups coming out with different recommendations. So how do you involve these disparate groups with different perspectives and values and then come down with a common set of recommendations? My feeling is the best way to get people together is on the evidence report. Involve professional societies with the technical advisory panel that advises the evidence report, so that when an evidence report comes out, there shouldn't be a lot of debate. Now, where you're going to get disagreement is recommendations that come from it. You may very well have primary care docs say "We don't think we ought to be doing this until we get the evidence" and you're going to have specialists out there who make their living doing those things who say, "Oh, we should continue to do this until we get the evidence." But, at least everybody agrees this is the current status of the evidence. --- Professional Society Member #12

I think the people who are most skeptical about accepting [recommendations] feel the recommendations go against some of the professional societies. So I think that having members of these professional societies on an advisory board or panel to contribute to the discussion and then in turn, take it back to their societies [would be helpful]. I know

that's probably a pipe dream, but I think that sort of collaboration would enhance people's belief in the recommendations. --- Professional Society Member #16

I think that a big mistake is made when we do top-down dissemination and not getting out into the ranks and starting at a grass roots level. Almost all states have annual meetings, but there's a couple of states that don't and there's a few states that have two or three. There are regions that get together. There's various ways of sharing a message on a very local level that makes people feel included and gets them excited. Some of the big national organizations are unwieldy and those boats are really slow to turn. They don't always have time to reach out to their states. --- Professional Society Member #16

4.10 Summary of Main Findings

There were differing views on the meaning of “evidence-based”, but there was broad agreement on its scientific underpinning and the importance of conducting “evidence-based practice.” Professional societies can play several roles (i.e., disseminator, liaison, developer, and/or facilitator) in the promotion of evidence-based recommendations and practice. Views varied on whether the needs of primary care providers and their professional societies for evidence-based reports and recommendations were being met. Federally-sponsored recommendation developers were viewed as valuable contributors to evidence-based practice because of their objectivity, transparency, balance, methodological rigor, and prioritization. Study participants offered many suggestions for improving the development, feasibility, readability, acceptability, and dissemination of evidence-based recommendations. Participants also offered input on how federally-sponsored recommendation developers could strengthen their partnerships with stakeholders, including professional societies and their members.

A list of all major study findings is provided below.

- 1) There were differing views on the meaning of “evidence-based”, but there was broad agreement on its scientific underpinning and the importance of conducting “evidence-based practice.”

- 2) Professional societies can play several roles (disseminator, liaison, developer, and/or facilitator) in the promotion of evidence-based recommendations and practice.
- 3) Views varied on whether scientific panels were meeting the needs of professional societies for evidence-based recommendations.
- 4) Federally-sponsored panels are valuable contributors to evidence-based practice because of their objectivity, transparency, balance, methodological rigor, and prioritization.
- 5) Professional societies often have shared governance and formalized procedures, and maintain highly knowledgeable members.
- 6) Size and system openness varied, but were associated with self-reported innovativeness among professional society leaders.
- 7) A patient's values and circumstances should be considered when weighing the benefits and harms of evidence-based recommendations.
- 8) High quality, evidence-based recommendations were considered valuable, but not always available.
- 9) Views varied on what was an acceptable level of evidence, but many supported a transparent process to assess the quality of evidence and strength of recommendations.
- 10) There was general awareness of scientific panels and/or their sponsoring organizations, but little in-depth knowledge about panel composition and procedures.
- 11) Conflicts of interest (COI) impacted panel trust, but there were perceived gradations of COI and disagreement on whether conflicted, but knowledgeable experts should serve on panels.
- 12) There was support for panel diversity, but respondents noted caution and caveats when considering lay persons as panelists.
- 13) There was support for internal and external reviews, but some concern about asking the general public for comments.
- 14) Clinicians often felt overwhelmed by information, but electronic support systems lessen the burden.
- 15) The National Guideline Clearinghouse (NCG) has the potential to support providers, but the service needs improvement.

- 16) Evidence-based recommendations can affect professional practice and satisfaction, but providers believe there is often latitude within recommendations to incorporate clinical expertise and patient factors.
- 17) Professional tensions were noted, most frequently between academicians involved in developing recommendations and the rank and file clinicians involved in implementing them.
- 18) Clinicians tried to follow panel recommendations, with the caveat that there were always exceptions for patients with unusual circumstances or characteristics.
- 19) Clinicians resolve the heterogeneity of recommendations in different ways and often share decision-making with their patients.
- 20) Contextual factors (e.g., access to facilities, regional practices, patient beliefs, enabling resources, perceived need, provider preferences) impacted the utilization of evidence-based recommendations.
- 21) Clinicians have some influence in modifying contextual factors, but barriers remain and inhibit utilization of health care services.

CHAPTER 5: DISCUSSION

The overall goal of this study was to identify the role of federal scientific panels in promoting evidence-based practice and how federally-sponsored panels can better meet the needs of primary care providers and their professional societies for evidence-based reports and recommendations. In working toward this goal, the principal investigator: 1) collected insights for enhancing current and future federally-sponsored panels, programs, and initiatives, and 2) developed original knowledge to contribute to social and behavioral sciences research.

The use of nonprobability, purposive sampling did not permit generalization from the sample of professional society members and leaders to the wider population, but it did provide the opportunity to gain an in-depth understanding of:

- Knowledge, attitudes, and beliefs about evidence-based practice and scientific panels (including the CDP)
- Utilization of panel reports and the contextual factors that facilitate or impede the implementation of evidence-based recommendations
- Professional society characteristics, activities, innovativeness, and roles in promoting evidence-based practice
- Professional practice and control (including professional tension, autonomy, and satisfaction)
- The value federally-sponsored panels provide in supporting evidence-based practice
- Suggestions for improving panel recommendations and promoting their diffusion through professional societies.

Although the topic of colorectal cancer (CRC) screening served as a starting point for discussion with study participants, their responses were not limited to issues regarding CRC screening recommendations. Leaders and members focused largely on evidence-based recommendations in general; therefore, their responses can be viewed as covering evidence-based recommendations more broadly.

Data were compared across professional societies and between leaders and members. Although there were differences among professional societies (i.e., size, system openness, and organizational innovativeness), there were no substantial differences noted between the responses of leaders and members. This homogeneity may be the result of gatekeeper bias since leaders helped identified members who could participate in the study. Leaders may have recommended members who were similar to themselves, resulting in congruent perspectives on a variety of issues.

There was a variety of views on the term “evidence-based.” Some federally-sponsored panels consider many levels of evidence; therefore, consistent grading of the quality of evidence and strength of recommendations would help clinicians distinguish their options. High levels of evidence are not always available for rare conditions and other diseases not conducive to large RCTs. NIH funding of new research methodologies could help strengthen the evidence available to clinicians who need guidance to care for these patients. Evidence-based screening recommendations are often geared toward populations that are asymptomatic and at average risk. As science provides more information about the individuality of medicine, additional methodologies may hold utility for panels and the investigators conducting research.

The issue of trust was central to attitudes and beliefs about scientific panels and their evidence-based reports and recommendations. Mayer, Davis, and Schoorman (1995) developed an Integrated Model of Organizational Trust that includes three factors that lead to trust: ability, benevolence, and integrity.

- Ability is a group of skills, competencies, and characteristics within a specific domain
- Benevolence is the extent to which one is believed to want to do good
- Integrity involves adhering to a set of acceptable principles. (Mayer, Davis, and Schoorman, 1995)

Study participants implied that these three factors (which require transparency to be assessed) increased the trustworthiness of reports and recommendations.

First, the participants valued panelists' abilities (based on a strong scientific background, clinical experience, or other pertinent knowledge and skills) to help elucidate the topic under consideration. Second, respondents alluded to the issue of benevolence as they expressed concerns about conflicts of interest that may put a panel's primary interest (i.e., to develop good recommendations that benefit patients) at risk because of personal interests (e.g., promote financial or intellectual gains). Third, participants described the need for a methodologically rigorous process steeped in integrity. Many respondents described the importance of following principles outlined in the 2011 IOM report on developing trustworthy guidelines and in the 2012 Council of Medical Specialty Societies report on *Principles for the Development of Specialty Society Clinical Guidelines*. The IOM report proposed eight standards, which address:

- (1) Transparency
- (2) Management of Conflict of Interest
- (3) Guideline Development Group Composition
- (4) Clinical Practice Guideline-Systematic Review Intersection
- (5) Establishing Evidence Foundations for and Rating Strength of Recommendations
- (6) Articulation of Recommendations
- (7) External Review
- (8) Updating

The Pathways to Prevention (P2P) program and other federal sponsors of scientific panels would benefit by adopting IOM or other well-regarded standards. Furthermore, the ODP and other federal offices could benefit by incorporating the factors of ability, benevolence, and integrity throughout their programs and initiatives.

There were conflicting opinions about the inclusion of patient advocates on scientific panels. The ODP has a policy of including a public representative on its panels, (e.g., economists, attorneys, ethicists, patient advocates) and the lead investigator of this study supports this policy after serving six years with the National Cancer Institute, Office of Advocacy Relations. Feedback from respondents suggests that if patient advocates are included, it would be beneficial if they have an understanding of pertinent medical issues and research methodology in order to more fully participate and contribute in panel activities. Patient advocate training programs, such as those sponsored by the American Association for Cancer Research, help patient advocates develop a stronger understanding of research and related issues (AACR, 2007). Federally-sponsored panels may benefit from recruiting advocates with similar training. Additionally, a short training (similar to that for the USPSTF) on evidence-based recommendations and practice, as well as panel processes, could be beneficial to all panelists.

Many clinicians feel overwhelmed by the high volume of reports and recommendations that are released each year. In an effort to assist clinicians, health plan administrators, and others, AHRQ has funded a free, online searchable database of clinical practice guidelines—the National Guideline Clearinghouse (NGC). However, much criticism has been levied at the NGC, some of which was included in IOM’s 2011 report:

The products listed within are of widely varying quality. The committee has heard testimony that the NGC performs a public service, but does not set sufficiently high standards to assure users that poor-quality guidelines are not admitted. Given the mixed quality of clearinghouse contents, its large volume is also problematic. AHRQ and [its NCG contractor] could take several steps to differentiate between trustworthy guidelines and others...to increase clearinghouse utility. (p. 196)

In response to the IOM report, the NGC developed new inclusion criteria that take affect beginning June 2014 (NGC, 2014b). These criteria include the need to show documentation that 1) a “guideline is based upon a systematic review of the evidence” and 2) an assessment of the benefits and harms of recommended and alternative care options has been conducted (NGC,

2014b). As one participant noted, the strengthening of inclusion criteria for the NGC will help “separate the wheat from the chaff” and assist clinicians in identifying quality recommendations.

Andersen’s Behavioral Model for Healthcare Utilization was a valuable framework for examining the contextual variables associated with the utilization of health care recommendations. Respondents noted that the environment, population characteristics, and health behaviors of both patients and providers impacted the use of recommendations. Although clinicians were resourceful and often successful in facilitating recommended services for those with inadequate or no insurance, many patients were unable to receive appropriate care in a timely manner. The Affordable Care Act (ACA) is expected to provide quality health care to millions of previously uninsured Americans, helping remove a key utilization barrier. Furthermore, the ACA covers preventive services recommendations that have an A or B rating from the USPSTF (AHRQ, 2014b). Increasing the capacity of the USPSTF and/or providing ACA coverage for other federally-sponsored panel recommendations could further reduce utilization barriers.

The large volume of findings in the health literature, coupled with recommendation heterogeneity, can be confusing and overwhelming to clinicians. Electronic health records and point-of-care decision support tools were helpful to study participants in learning about health recommendations and sharing them with patients.

Weed (1991) argued that clinical decision-making was a difficult and frustrating predicament for the ‘physician’s unaided mind’ given the tremendous increase in medical information and the complexity of patient needs. Weed (2004) recommended the use of two types of information tools [computer software and the medical record] for “1) bridging the gap between the physician’s mind and the unbearable burden of coupling patient data with medical knowledge, and 2) organizing the multiple processes involved in patient care” (p. 46).

The coupler principle is simple: gather a large number of variables (medical history findings, physical examination findings, and laboratory data) and use a computer to sort

them into all the diagnostic or treatment possibilities for that patient's unique clinical situation. The logic is combinatorial rather than probabilistic or algorithmic. Probabilistic logic would cause us to miss the rare possibility, and algorithmic logic forces an either-or decision, but in fact, there may be two simultaneous choices (migraine *and* muscle contraction headache) (Burger, 2010, p. 47).

Although knowledge couplers can make clinical care more manageable, in a recent interview, Weed dismissed current electronic health record systems (EHR) as inadequate and argued that the medical education system continues to perpetuate the myth that physicians can keep up—"In medicine, it's what does the doctor think? It's pathetic... When are they going to wake up and stop moving knowledge through heads and start moving knowledge through tools?" (Conn, 2013). The American Recovery and Reinvestment Act provided funding to promote electronic health records among primary care providers (HRSA, 2014) and Medicare and Medicaid EHR Incentive Programs provide payments to eligible professionals and hospitals as they "adopt, implement, or demonstrate meaningful use of certified electronic health record technology" (ONC-NLC, 2014). These federal efforts are important, but should be combined with more research on how to develop better software, training, and workflow adoption (Burger, 2010).

Scientific panels are meeting some of the need providers have for evidence-based reports and recommendations. However, there are gaps in the topics covered, confusing heterogeneity among recommendations, many poor quality recommendations, and there is a lack of transparency that inhibits a clinician's ability to directly and accurately evaluate and compare recommendations. The federal government can play an important role in addressing these issues by bolstering the National Guideline Clearinghouse; identifying evidence gaps; funding new, applicable research; and partnering with professional societies and other sponsoring organizations to harmonize recommendations.

Diffusion of Innovations was another useful framework for this study, as it permitted the examination of professional societies: their structure, activities, perceived innovativeness, and

promotion of evidence-based practice. The data collected in this study supports Rogers (2003) assertion that certain independent variables, specifically organizational size and external system openness, are associated with perceived organizational innovativeness. Federally-sponsored panels may benefit from approaching larger, more externally connected professional societies when seeking either official endorsements of their recommendations or opportunities to collaborate on joint recommendation development (Initiation Activities). For dissemination efforts (Implementation Activities), these larger societies, as well as smaller, less open organizations, can serve as excellent partners.

Professional societies play a variety of important roles in promoting evidence-based practice among their membership. Whether serving as disseminators, liaisons, direct developers of recommendations and measures, or as facilitators of evidence-based programs and initiatives, professional societies have resources which federally-sponsored panels could leverage through public/private partnerships. Professional societies aim to change provider practice through a variety of mechanisms:

- Journals and newsletters
- Official statements, bulletins, committee opinions, practice advice, guidelines, measures, and recommendations
- Conferences and meetings
- Strategic programs and initiatives.

Federally-sponsored panels should consider collaborating with professional societies on a combination of interventions to facilitate practice change. Panels and organizations may also want to work with state or regional chapters and key local opinion leaders to develop implementation plans for broader dissemination and to empower more rank and file clinicians to integrate evidence-based panel recommendations with their clinical expertise and patient values and circumstances.

Friedson (1984) noted conflict among the knowledge elite, administrative elite, and rank and file professionals. Study participants also described this tension and identified an additional tension between generalists and clinical subspecialists. An understanding of this tension is particularly helpful when navigating the often contentious debates regarding screening recommendations (e.g., prostate-specific antigen [PSA] testing, mammography for women aged 40-50 years). Efforts should be taken to help translate academic, epidemiologic recommendations into guidance that rank and file professionals can use when serving individual patients. It is important for panels to highlight any caveats, so clinicians are not asked to follow a ‘cookbook’, but rather, integrate the best available research with their clinical expertise. Furthermore, by fostering agreement on evidence reports, tension between generalists and subspecialists can be reduced as the two find common ground regarding the state of the science.

The lead investigator for this study is a former staff member of the Consensus Development Program and was admittedly disappointed when the 35-year old program was retired without an official evaluation to justify the decision. The investigator approached this study with the assumption that most professional society leaders, and many members, valued the CDP and its contributions to evidence-based practice. However, the results of this study indicated that only one-third of leaders and members had knowledge of the CDP. These well-respected experts most frequently sought evidence-based reports and recommendations from panels supported by other federal agencies, non-profit organizations, professional societies, or disease specific societies. Many that did have knowledge of the CDP were exposed to the program through an existing, collaborative relationship between the society and an NIH Institute or Center that had sponsored a CDP conference. The ODP should consider building on these existing public/private partnerships in order to successfully implement portions of its new strategic plan.

The CDP was created partly in response to a 1976 conclusion by the Congressional Office of Technology Assessment (OTA) that reviews of medical innovations would be useful in decision-making (Perry & Kalberer, 1980). By 2013, the CDP was retired with the justification that it

duplicated the work of other federal agencies, academic institutions, and private organizations (NIH-CDP, 2013). Interestingly, the OTA was also de-funded in part because it appeared to duplicate the work of others.

The Union of Concerned Scientists has argued that other entities (e.g., National Academy of Sciences, Congressional Research Service, and the Government Accountability Office) do not satisfactorily fill the role of the OTA.

- The [National Academy of Sciences] NAS provides excellent consensus recommendations from groups of the nation's most respected scientists and experts. But advising Congress is not its primary function and while it tries to be responsive to congressional requests, it can and does say no at times. Furthermore, the NAS is not always attuned to the needs and timelines of legislators and its reports are very expensive to produce. As a non-governmental agency, the NAS lacks sufficient high-level access to other parts of the federal government.
- The [Congressional Research Service] CRS is highly respected for its rapid response, but it is not accustomed to working with stakeholders or outside experts. It does not have the necessary technological or analytical capacity of the OTA, nor does it have experience with peer review.
- The [Government Accountability Office] GAO has very recently begun to undertake technological assessments of the type formerly done by OTA, but that program is bound by the rules and culture of a financial auditing agency. While the GAO has extensive access to all parts of the federal government and has produced numerous reports that have proven extremely useful for oversight, it has little experience with forward-looking assessments. Given the GAO's core mission, it is unlikely that technology assessment will find a permanent home at GAO. (UCS-2010)

It is unclear if the U.S. Preventive Services Task Force, the Community Preventive Services Task Force, the Institute of Medicine, The Cochrane Collaboration, and other entities will fill the vacuum that might have been left by the retirement of the CDP. Some federal and non-federal researchers have expressed concern that the rigorous, transparent, and objective processes of the CDP are not followed by other entities, especially when assessing treatment modalities. However, the NIH is stepping away from clinical recommendation and guideline development and is

unlikely to reverse course in the near future. For example, NHLBI announced in June 2013 that it will no longer develop clinical practice guidelines and will instead focus on generating high-quality systematic reviews to support the “development of clinical practice guidelines through partnerships with professional societies and other organizations” (NHLBI, 2013). The NIH is shifting its focus away from clinical guideline development back to its core mission—scientific discovery—and relying more heavily on partnerships to support diffusion. This shift may be appropriate for the ODP, given that the influence of the CDP with health providers was mixed (Kosecoff et al. 1987 and 1990), while CDP statements appeared to stimulate new, relevant research activities, including NIH-issued initiatives and investigator-initiated grants (Portnoy et al., 2007). It is hoped that the P2P program will successfully identify important prevention-related research gaps using a less expensive and more facile process than its predecessor and that the ODP will help bridge those gaps by supporting prevention research and working with key stakeholders to move research into practice.

The recommendations in this study can advance public health with their attention to both individual and social environmental factors (McLeroy, Bibeau, Steckler, & Glanz, 1988). Professional society leaders and members addressed intrapersonal factors (e.g., multi-faceted interventions aimed at changing provider practice), institutional factors (e.g., changes in program policies regarding panel composition and processes), community factors (e.g., enhancing relationships among federally-sponsored panels and professional societies), and public policy (e.g., expanding insurance coverage for preventive services and counseling) (McLeroy, Bibeau, Steckler, & Glanz, 1988). Beyond its support of scientific panels, the federal government can promote evidence-based practice across a range of health determinants at both individual and population levels.

Study Limitations

Tuckett (2004) notes two limitations that were applicable to this study: sample frame bias and gatekeeper bias. The study population included leaders and members of U.S.-based primary care professional societies (or primary care segments of broader associations) that are national in focus and which address colorectal cancer screening issues through position statements or clinical recommendations. This study population was chosen because it captures organizations that were the target of CDP outreach efforts. However, there are many health-related professional societies (serving generalists and subspecialists from different areas of the country) which were not eligible for this study, but who at times were also involved with CDP conferences. A larger sampling frame might have captured more variation in stakeholder perspectives and added to the richness of the data.

The study involved expert and snowball sampling of professional society leaders and members. Society Presidents, Chief Executive Officers, and a Board Member served as gatekeepers for recruitment and therefore had control of sampling. Over half of the members invited to participate in the study were involved in academia, and only one member served as an administrator to rank and file clinicians. A more diverse selection of participants may have added additional perspectives about professional tensions, determinants of provider practice, and how to make recommendations more feasible to implement.

Telephone interviews permitted access to leaders and members from across the country, enabled discussion to be easily recorded, and eliminated travel time and expense. However, the telephone interviews reduced social cues, such as body language, which can be used as additional sources of information. Interview data limitations also included possibly distorted responses due to personal bias, reactivity of the interviewee to the interviewer(s), and self-serving purposes (Patton, 2002).

Lastly, the lead researcher came to this study with her own biases, which included disappointment in the retirement of the CDP, belief that the federal government substantially contributes to evidence-based practice, and support for the inclusion of lay members on scientific

panels. She continues to support public representatives on panels, so long as the panelists have pertinent knowledge to elucidate the topic under consideration and training to facilitate their successful participation. The researcher's belief that the federal government adds value to evidence-based practice is supported by this research, and although feedback from many leaders and members challenged some of her views about the CDP, the study findings have fostered optimism about the potential impact of the new Pathways to Prevention program and other ODP initiatives outlined in the Office's strategic plan.

APPENDICES

Appendix 1: Listing of Initial 19 National Guideline Clearinghouse Entries and Sponsoring Organizations

19 National Guideline Clearinghouse Entries

- (1) [NIH State-of-the-Science Conference Statement on enhancing use and quality of colorectal cancer screening](#). 2010 Feb. NGC:008272
National Institutes of Health Consensus Development Conference - Independent Expert Panel.
- (2) [Colorectal cancer screening clinical practice guideline](#). 2006 Nov (revised 2008 Dec). NGC:007213
Kaiser Permanente Care Management Institute - Managed Care Organization.
- (3) [ACR Appropriateness Criteria® colorectal cancer screening](#). 1998 (revised 2010). NGC:007920
American College of Radiology - Medical Specialty Society.
- (4) [Colorectal cancer screening](#). 1995 May (revised 2010 May). NGC:007960
Institute for Clinical Systems Improvement - Nonprofit Organization.
- (5) [Colorectal cancer screening](#). 2007. NGC:006244
World Gastroenterology Organisation - Medical Specialty Society.
- (6) [Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement](#). 1996 (revised 2008 Oct). NGC:006722
U.S. Preventive Services Task Force - Independent Expert Panel.
- (7) Guideline Synthesis [Screening for Colorectal Cancer](#).
- (8) [Preventive services for adults](#). 1995 Jun (revised 2010 Sep). [NGC Update Pending] NGC:008086
Institute for Clinical Systems Improvement - Nonprofit Organization.
- (9) [Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps. 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology](#). 2001 (revised 2008 May-Jun). NGC:007214
American Cancer Society - Disease Specific Society; American College of Radiology - Medical Specialty Society; U.S. Multisociety Task Force on Colorectal Cancer - Medical Specialty Society.
- (10) [Adult preventive services \(ages 50 - 65+\)](#). 2005 Jul (revised 2011 Apr). NGC:008506
Michigan Quality Improvement Consortium - Professional Association.
- (11) [Endoscopy by nonphysicians](#). 2009 Apr. NGC:008327
American Society for Gastrointestinal Endoscopy - Medical Specialty Society.
- (12) [Adult preventive services \(ages 18 - 49\)](#). 2005 Jul (revised 2011 Apr). NGC:008505
Michigan Quality Improvement Consortium - Professional Association.
- (13) [Diagnosis and management of primary sclerosing cholangitis](#). 2010 Feb. NGC:007676
American Association for the Study of Liver Diseases - Nonprofit Research Organization.
- (14) [Gastroscopy following a positive fecal occult blood test and negative colonoscopy: guideline recommendations](#). 2009 Mar 30. NGC:007276
Program in Evidence-based Care - State/Local Government Agency [Non-U.S.].
- (15) [Prevention and screening of colorectal cancer](#). 2002 Apr 27 (revised 2008 May 22). NGC:006598
Finnish Medical Society Duodecim - Professional Association.
- (16) [ASGE guideline: modifications in endoscopic practice for the elderly](#). 2006 Apr (reaffirmed 2011). NGC:004975
American Society for Gastrointestinal Endoscopy - Medical Specialty Society.
- (17) [Use of tumor markers in testicular, prostate, colorectal, breast, and ovarian cancers](#). 2009. NGC:007630
National Academy of Clinical Biochemistry - Professional Association.

- (18) [Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 137-146: cancer and general health screening.](#) 2003 Sep (revised 2008 Oct).
NGC:007574
Children's Oncology Group - Medical Specialty Society.
- (19) [Summary of recommendations for clinical preventive services.](#) 1996 Nov (revised 2011 May).
[NGC Update Pending] NGC:008564
American Academy of Family Physicians - Medical Specialty Society.

Sponsoring Organizations

American Academy of Family Physicians
American Association for the Study of Liver Diseases
American Cancer Society
* American College of Gastroenterology
American College of Radiology
* American Gastroenterological Association
* American Society for Gastrointestinal Endoscopy
Children's Oncology Group
Finnish Medical Society Duodecim
Institute for Clinical Systems Improvement
Kaiser Permanente Care Management Institute
Michigan Quality Improvement Consortium
National Academy of Clinical Biochemistry
National Institutes of Health Consensus Development Conference
Program in Evidence-based Care
U.S. Preventive Services Task Force
World Gastroenterology Organisation

* Organization represented by the U.S. Multisociety Task Force on Colorectal Cancer

Appendix 2: Division of Initial 19 National Guideline Clearinghouse Entries

Included in study:

- #1 NIH State-of-the-Science Conference Statement on enhancing use and quality of colorectal cancer screening. 2010 Feb. NGC:008272
National Institutes of Health Consensus Development Conference - Independent Expert Panel.
- # 6 Screening for colorectal cancer: U.S. Preventive Services Task Force recommendation statement. 1996 (revised 2008 Oct). NGC:006722
U.S. Preventive Services Task Force - Independent Expert Panel.
- #9 Screening and surveillance for the early detection of colorectal cancer and adenomatous polyps, 2008: a joint guideline from the American Cancer Society, the US Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology. 2001 (revised 2008 May-Jun). NGC:007214
American Cancer Society - Disease Specific Society; American College of Radiology - Medical Specialty Society; U.S. Multisociety Task Force on Colorectal Cancer - Medical Specialty Society.
- #19 Summary of recommendations for clinical preventive services. 1996 Nov (revised 2011 May). [NGC Update Pending] NGC:008564
American Academy of Family Physicians - Medical Specialty Society.

Excluded from study:

- # 2 Colorectal cancer screening clinical practice guideline. 2006 Nov (revised 2008 Dec). NGC:007213
Kaiser Permanente Care Management Institute - Managed Care Organization. *Exclusion Criterion: Not national in focus.*
- # 3 ACR Appropriateness Criteria® colorectal cancer screening. 1998 (revised 2010). NGC:007920 American College of Radiology - Medical Specialty Society. *Exclusion Criterion: Duplicative of joint recommendation in #9 above.*
- # 4 Colorectal cancer screening. 1995 May (revised 2010 May). NGC:007960
Institute for Clinical Systems Improvement - Nonprofit Organization. *Exclusion Criterion: Not national in focus.*
- # 5 Colorectal cancer screening. 2007. NGC:006244
World Gastroenterology Organisation - Medical Specialty Society. *Exclusion Criterion: International panel.*
- # 7 Guideline Synthesis Screening for Colorectal Cancer. *Exclusion Criterion: Guideline synthesis conducted by AHRQ regarding 3 recommendations listed above (#2, #6, #9).*
- # 8 Preventive services for adults. 1995 Jun (revised 2010 Sep). [NGC Update Pending] NGC:008086
Institute for Clinical Systems Improvement - Nonprofit Organization. *Exclusion Criterion: Not national in focus.*
- #10 Adult preventive services (ages 50 - 65+). 2005 Jul (revised 2011 Apr). NGC:008506
Michigan Quality Improvement Consortium - Professional Association. *Exclusion Criterion: Not national in focus.*
- #11 Endoscopy by nonphysicians. 2009 Apr. NGC:008327
American Society for Gastrointestinal Endoscopy - Medical Specialty Society. *Exclusion Criterion: Duplicative of joint recommendation in #9 above.*

- #12 Adult preventive services (ages 18 - 49). 2005 Jul (revised 2011 Apr). NGC:008505
Michigan Quality Improvement Consortium - Professional Association. *Exclusion Criterion: Not national in focus.*
- #13 Diagnosis and management of primary sclerosing cholangitis. 2010 Feb. NGC:007676
American Association for the Study of Liver Diseases - Nonprofit Research Organization. *Exclusion Criterion: Focus is primary sclerosing cholangitis not CRC screening for people at average risk of colorectal cancer.*
- #14 Gastroscopy following a positive fecal occult blood test and negative colonoscopy: guideline recommendations. 2009 Mar 30. NGC:007276
Program in Evidence-based Care - State/Local Government Agency [Non-U.S.]. *Exclusion Criterion: International panel.*
- #15 Prevention and screening of colorectal cancer. 2002 Apr 27 (revised 2008 May 22). NGC:006598
Finnish Medical Society Duodecim - Professional Association. *Exclusion Criterion: International panel.*
- #16 ASGE guideline: modifications in endoscopic practice for the elderly. 2006 Apr (reaffirmed 2011). NGC:004975
American Society for Gastrointestinal Endoscopy - Medical Specialty Society. *Exclusion Criterion: Duplicative of joint recommendation in #9 above.*
- #17 Use of tumor markers in testicular, prostate, colorectal, breast, and ovarian cancers. 2009. NGC:007630
National Academy of Clinical Biochemistry - Professional Association. *Exclusion Criterion: Does not focus on common screening modalities.*
- #18 Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Sections 137-146: cancer and general health screening. 2003 Sep (revised 2008 Oct). NGC:007574
Children's Oncology Group - Medical Specialty Society. *Exclusion Criterion: Does not focus on people at average risk of colorectal cancer.*

Appendix 3: Organizations, Panels, and Recommendations or Conclusions

Independent Expert Panels and Their Supporting Organizations

1) The NIH is the nation's medical research agency and the largest source of funding for medical research in the world (NIH, 2014). The ODP is the lead office at NIH "responsible for assessing, facilitating, and stimulating research in disease prevention and health promotion, and disseminating the results of this research to improve public health" (ODP, 2014a). The ODP's Consensus Development Program convened panels in which members were highly regarded in their own fields, but did not have financial or career interests related to conference topics. In February 2010, a CDP conference was held to assess the available data on enhancing the use and quality of colorectal cancer screening. A one-time, independent State-of-the-Science Panel of 13 non-federal members reviewed the results of a systematic literature review, listened to presentations conducted by experts of CRC issues, participated in public question and answer sessions, and deliberated in closed sessions. Afterward, the panel authored a 31-page consensus statement. Below are the major CDP recommendations.

The panel finds that despite substantial progress toward higher colorectal cancer screening rates nationally, screening rates fall short of desirable levels. Targeted initiatives to improve screening rates and reduce disparities in underscreened communities and population subgroups could further reduce colorectal cancer morbidity and mortality. This could be achieved by utilizing the full range of screening options and evidence-based interventions for increasing screening rates. With additional investments in quality monitoring, Americans could be assured that all screening achieves high rates of cancer prevention and early detection. To close the gap in screening, this report identifies the following priority areas for implementation and research to enhance the use and quality of colorectal cancer screening:

- Eliminate financial barriers to colorectal cancer screening and appropriate follow-up.
- Widely implement interventions that have proven effective at increasing colorectal cancer screening, including patient reminder systems and one-on-one interactions with providers, educators, or navigators.
- Conduct research to assess the effectiveness of tailoring programs to match the characteristics and preferences of target population groups to increase colorectal cancer screening.
- Implement systems to ensure appropriate follow-up of positive colorectal cancer screening results.
- Develop systems to ensure high quality of colorectal cancer screening programs.
- Conduct studies to determine the comparative effectiveness of the various colorectal cancer screening methods in usual practice settings.

National Guideline Clearinghouse: <http://www.guideline.gov/content.aspx?id=25654>

2) The Agency for Healthcare Research and Quality (AHRQ), which focuses on research that improves informed decision-making and the quality of health care services (AHRQ, 2011a) is congressionally mandated to support the U.S. Preventive Services Task Force (USPSTF). The USPSTF is an independent panel of 16 non-federal primary care clinicians who are experts in prevention and evidence-based medicine. The Task Force "conducts rigorous, impartial assessments of the scientific evidence for the effectiveness of a broad range of clinical preventive services, including screening, counseling, and preventive medications. Its evidence-based

recommendations are considered the “gold standard” for clinical preventive services” (AHRQ, 2010b). In 1996, the USPSTF recommended screening with gFOBT or FS (Coughlin & Thompson, 2005); by 2002 their recommendation included the use of colonoscopy (AHRQ, 2010b); and by 2008, FIT was added as a recommended screening option (AHRQ, 2008). Below is a summary of the 2008 USPSTF recommendations for CRC screening.

The USPSTF recommends screening for colorectal cancer using fecal occult blood testing, sigmoidoscopy, or colonoscopy, in adults, beginning at age 50 years and continuing until age 75 years. The risks and benefits of these screening methods vary. See Rationale section of the original guideline document. This is an A recommendation.

The USPSTF recommends against routine screening for colorectal cancer in adults 76 to 85 years. There may be considerations that support colorectal cancer screening in an individual patient. This is a C recommendation.

The USPSTF recommends against screening for colorectal cancer in adults older than age 85 years. This is a D recommendation.

The USPSTF concludes that the evidence is insufficient to assess the benefits and harms of computed tomographic colonography and fecal DNA testing as screening modalities for colorectal cancer. This is an I “*Insufficient Evidence*” statement.

National Guideline Clearinghouse: <http://www.guideline.gov/content.aspx?id=13133>

3) The Centers for Disease Control and Prevention (CDC), the leading federal division for public health, provides scientific, technical, and administrative support to the Community Preventive Services Task Force (CDC-Task Force, 2011). This Task Force is an independent panel of 12 non-federal public health and prevention experts, who are appointed to the Task Force by the Director of the CDC (CDC-Task Force, 2010a). The Task Force is charged with conducting systematic reviews and issuing findings and evidence-based recommendations to “help inform decision making about policy, practice, research, and research funding in a wide range of U.S. settings” (CDC-Task Force, 2010a). Below is a summary of the Task Force’s recommendations for the CRC screening.

Task Force Findings: 1/1/1997 -7/12/2010

Cancer Prevention and Control: Increasing Colorectal Cancer Screening

Client-Oriented Interventions

- Client Incentives – Insufficient Evidence 7/12/2010
- Client Reminders – Recommended (Sufficient Evidence) 2/26/2003
- Group Education – Insufficient Evidence 10/15/2000
- Mass Media - Insufficient Evidence 10/15/2000
- Small Media - Recommended (Strong Evidence) 12/15/2005
- One on One Education - Recommended (Sufficient Evidence) 3/31/2010
- Reducing Out-of-Pocket Costs - Insufficient Evidence 10/15/2009
- Reducing Structural Barriers - Recommended (Strong Evidence) 3/31/2010

Provider-Oriented Interventions

Provider Assessment and Feedback - Recommended (Sufficient Evidence) 10/15/2009
Provider Incentives - Insufficient Evidence 10/15/2009
Provider Reminders and Recalls - Recommended (Strong Evidence) 2/16/2006
Multicomponent Interventions - Recommended (Strong Evidence) 2/27/2008

The Community Guide:

http://www.thecommunityguide.org/about/Conclusion_Report_071210.pdf

Disease Specific Society

4) The American Cancer Society (ACS), “a nationwide, community-based voluntary health organization dedicated to eliminating cancer as a major health problem”, has “13 chartered Divisions and more than 3,400 local offices” (ACS, 2010). Since 1980, with the publishing of *Guidelines for the Cancer-Related Checkup: Recommendations and Rationale*, the ACS has conducted assessments of cancer screening tests (Smith et al. 2000). Prior to the mid-2000s, the ACS developed CRC screening guidelines through periodic workshops convened by its Colorectal Cancer Advisory Group using a nine-step process to review data and establish recommendations for target groups (Smith et al. 2000; Smith et al. 2001). In 2006-2007, the ACS joined the U.S. Multisociety Task Force on Colorectal Cancer (MSTF) and the American College of Radiology (ACR) to develop guidelines to screen for CRC and its precursor polyps (Levin et al. 2008). See Appendix C for the major points of the joint guidelines (NGC, 2008c).

Medical Specialty Societies

5) The American Academy of Family Physicians (AAFP), a national association of family doctors with approximately 100,000 members (AAFP, 2012a), has four stated objectives:

- Advocacy - Shape health care policy through interactions with government, the public, business, and the healthcare industry
- Practice Enhancement - Enhance members’ abilities to fulfill their practice and career goals
- Education - Promote high-quality, innovative education for physicians, residents, and medical students that encompasses the art, science, evidence and socioeconomics of family medicine
- Health of the Public - Assume a leadership role in health promotion, disease prevention, and chronic disease management. (AAFP, 2012b)

The AAFP Commission on Health of the Public and Science (CHPS) reviews external recommendations and makes its own recommendations, all of which are submitted to the AAFP Board of Directors for approval. In most cases the AAFP agrees with the USPSTF; however, there are circumstances where there are differences (AAFP, 2011). The 2011 CHPS recommendations for CRC screening mirrored those of the USPSTF (NGC, 2011).

6) The American College of Radiology has approximately 34,000 members, including “radiologists, radiation oncologists, medical physicists, interventional radiologists and nuclear medicine physicians” (ACR, 2011a). The mission of ACR is to maximize the profession’s value by advancing radiological science, improving patient care, addressing socioeconomic (i.e., reimbursement) issues, and providing continuing education for radiology and allied health professionals (ACR, 2011a; 2011b). The ACR Commission on Quality and Safety (CQS), which oversees development of the society’s radiology guidelines, tasks the Expert Panel on Gastrointestinal Imaging to create its CRC screening guidelines (ACR, 2011c, NGC, 2010b).

Draft clinical practice guidelines are posted on the ACR website for a 3-week ‘field review’, during which time any member of the society can provide comments (ACR, 2011d). These comments are collated by ACR staff and reviewed by a subcommittee that adopts or rejects suggested changes. Guidelines are then submitted as resolutions to be considered at the ACR Annual Meeting and Chapters Leadership Conference. Once adopted, guidelines are posted on the ACR website. In 2008, a sub-group of the Expert Panel on Gastrointestinal Imaging (Colon Cancer Committee) joined the American Cancer Society and the U.S. Multisociety Task Force on Colorectal Cancer to develop guidelines to screen for CRC and its precursor polyps (Levin et al. 2008). See Table 2 for the major points of the joint guidelines.

7-9) The U.S. Multisociety Task Force on Colorectal Cancer (MSTF) issued CRC screening guidelines in 1997, 2003, and 2008. For the last report, the MSTF issued joint recommendations with ACS and ACR (NCG, 2008c). The 2008 MSTF included members representing the American Gastroenterological Association, the American College of Gastroenterology, and the American Society for Gastrointestinal Endoscopy (Levin et al., 2008; McFarland et al., 2008). See Appendix 3 for the major points of the joint ACS, ACR, and MSTF 2008 guidelines, and below for descriptions of the three MSTF member organizations.

- (7) The American Gastroenterological Association (AGA), representing 17,000 members, focuses on the “science, practice and advancement of gastroenterology” (AGA, 2012a). The AGA maintains 13 committees, including the 11-member Practice & Quality Management Committee which is concerned with:
 - Developing evidence-based clinical practice guidelines; policy statements; consensus statements, etc., for gastroenterologists and primary care physicians with respect to the management and treatment of patients with various digestive diseases and conditions
 - Developing priorities, standards and processes for development of standards of practice (development of which shall be the responsibility of the AGA Council) (AGA, 2012b).
- (8) The American College of Gastroenterology (ACG) has 12,000 members and directs its efforts toward continuing medical education (through publications, meetings, and web-based resources), health care policy, clinical research, and patient advocacy (ACG, 2012a). The ACG Practice Parameters Committee follows specific steps when creating the organization’s clinical guidelines:
 - A subgroup of the committee holds a conference call to isolate 8-12 central issues in diagnosis and management of a disease.
 - Clinical questions are developed and applicable systematic reviews of evidence are identified.
 - Evidence from systematic reviews is linked to certain questions. When a clinical question is not addressed by a systematic review, an ‘explicit review of the literature’ is conducted, which may take cohort studies and case series findings under consideration.
 - Recommendations are generated using nominal group technique and are graded for both strength of evidence and strength of recommendation.
 - Flow diagrams demonstrating algorithms are created.
 - The ACG Board of Trustees reviews all recommendations, which are then published in the peer-reviewed *American Journal of Gastroenterology* for member comment. (ACG, 2012b).

The guideline development process takes approximately one year to complete.

- (9) The American Society for Gastrointestinal Endoscopy (ASGE), which has 12,000 members, is dedicated to advocacy, education, practice, and research that enhances digestive tract endoscopy (ASGE, 2012a). Physician members are required to have documented special training in gastrointestinal endoscopic procedures, such as flexible sigmoidoscopy and colonoscopy (ASGE, 2012a). The ASGE Standards of Practice Committee develops the organization's clinical practice guidelines (ASGE, 2012b). The Standards of Practice Committee routinely includes three representatives from other professional societies (i.e. Society of Gastroenterology Nurses and Associates (SGNA), Society of American Gastrointestinal and Endoscopic Surgeons (SAGES) and North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN)) when authoring clinical recommendations (NGC, 2006 & 2009).

Below are the MSTF Guidelines for Screening for the Early Detection of Colorectal Cancer and Adenomas for Average-Risk Women and Men Aged 50 Years and Older

The following options are acceptable choices for colorectal cancer screening in average-risk adults beginning at age 50 years. Since each of the following tests has inherent characteristics related to prevention potential, accuracy, costs, and potential harms, individuals should have an opportunity to make an informed decision when choosing one of the following options.

In the opinion of the guidelines development committee, *colon cancer prevention* should be the primary goal of colorectal cancer screening. Tests that are designed to detect both early cancer and adenomatous polyps should be encouraged if resources are available and patients are willing to undergo an invasive test.

Tests that Detect Adenomatous Polyps and Cancer		
Test	Interval	Key Issues for Informed Decisions
Flexible sigmoidoscopy (FSIG) with insertion to 40 cm or to splenic flexure	Every 5 years	<ul style="list-style-type: none"> Complete or partial bowel prep is required Sedation usually is not used, so there may be some discomfort during the procedure The protective effect of sigmoidoscopy is primarily limited to the portion of the colon examined Patients should understand that positive findings on sigmoidoscopy usually result in a referral for colonoscopy
Colonoscopy	Every 10 years	<ul style="list-style-type: none"> Complete bowel prep is required Conscious sedation is used in most centers; patients will miss a day of work and will need a chaperone for transportation from the facility Risks include perforation and bleeding, which are rare but potentially serious; most of the risk is associated with polypectomy
Double contrast barium enema (DCBE)	Every 5 years	<ul style="list-style-type: none"> Complete bowel prep is required If patients have one or more polyps ≥ 6 mm, colonoscopy will be recommended; follow-up colonoscopy will require complete bowel prep Risks of DCBE are low; rare cases of perforation have been reported
Computed tomographic colonography (CTC)	Every 5 years	<ul style="list-style-type: none"> Complete bowel prep is required If patients have one or more polyps ≥ 6 mm, colonoscopy will be recommended; if same day colonoscopy is not available, a second complete bowel prep will be required before colonoscopy Risks of CTC are low; rare cases of perforation have been reported Extracolonic abnormalities may be identified on CTC that could require further evaluation
Tests that Primarily Detect Cancer		
Test	Interval	Key Issues for Informed Decisions
Guaiac-based fecal occult blood test (gFOBT) with high sensitivity for cancer	Annual	<ul style="list-style-type: none"> Depending on manufacturer's recommendations, 2 to 3 stool samples collected at home are needed to complete testing; a single sample of stool gathered during a digital exam in the clinical setting is not an acceptable stool test and should not be done Positive tests are associated with an increased risk of colon cancer and advanced neoplasia; colonoscopy should be recommended if the test results are positive If the test is negative, it should be repeated annually Patients should understand that one-time testing is likely to be ineffective
Fecal immunochemical test (FIT) with high sensitivity for cancer	Annual	
Stool DNA (sDNA) with high sensitivity for cancer	Interval uncertain	<ul style="list-style-type: none"> An adequate stool sample must be obtained and packaged with appropriate preservative agents for shipping to the laboratory The unit cost of the currently available test is significantly higher than other forms of stool testing If the test is positive, colonoscopy will be recommended If the test is negative, the appropriate interval for a repeat test is uncertain

Note: In this update of the CRC screening guidelines, the guideline authors have focused on screening in average-risk adults and have not reviewed recent literature on CRC screening or surveillance for individuals at increased and high risk. Individuals at increased risk due to a history of adenomatous polyps; a personal history of curative-intent resection of CRC; a family history of either CRC or colorectal adenomas diagnosed in a first-degree relative before age 60 years; or high risk due to a history of inflammatory bowel disease of significant duration or the presence of one of two hereditary syndromes should continue to follow recommendations issued previously by the American Cancer Society (ACS) or U.S. Multi-Society Task Force (USMSTF).

National Guideline Clearinghouse: <http://www.guideline.gov/content.aspx?id=14346>

Nonprofit Organizations

10) The Cochrane Collaboration is an international, nonprofit organization that conducts systematic reviews of research in health care and health policy to help clinicians, patients, advocates, and policymakers make well-informed decisions based on the best available evidence (Cochrane Collaboration, 2012a & 2012b). The Cochrane Colorectal Cancer Group (CCCG) is one of the organization's 52 collaborative review groups (Cochrane Collaboration, 2009). The CCCG is composed of 13 editors, 2 consumer representatives, 600 reviewers, 120 external peer referees, and 21 searchers. A search of The Cochrane Library, using the search term "colorectal", yielded 89 reviews and protocols. Of the 89, five were related to colorectal cancer screening of asymptomatic, average-risk adults; one review and four protocols (Cochrane Collaboration, 2012c). A plain language summary for the published 2011 review on FOBT highlights the following evidence-based findings:

- Regular screening of faeces for blood can detect colorectal cancer earlier and hence may reduce mortality.
- If the FOBT is positive, the bowels are examined closely with further diagnostic testing (colonoscopy, flexible sigmoidoscopy, double-contrast barium enema), but these tests often cause discomfort and can cause serious adverse consequences. As blood identified in faeces may be due to several reason (unrelated to cancer), it may cause people unnecessary stress and expose them to possible harm.
- FOBT screening is likely to avoid approximately 1 in 6 colorectal cancer deaths. (Cochrane Collaboration, 2008, 2)

11) The Institute of Medicine (IOM), the health arm of the National Academy of Sciences, is an independent, nonprofit organization that works to provide unbiased and authoritative advice about health and health care to decision-makers and the public (IOM, 2010). Many studies that the IOM conducts are congressionally mandated; however, federal agencies and independent organizations can also request an IOM review through consensus committee, standing committee, workshop, forum, or roundtable (IOM, 2010). In 2008, the IOM's National Cancer Policy Forum (NCPF) convened a workshop on CRC screening to discuss the next steps to be taken by clinics, communities, and health systems to overcome screening barriers and prevent CRC deaths (IOM, 2008). The NCPF consists of 20 members, representing cancer centers, advocacy organizations, industry, academia, and components of the U.S. Department of Health and Human Services. The Forum's 2008 evidence-based report from the workshop was independently reviewed by five experts to ensure the manuscript met the IOM's standards for objectivity, evidence, and responsiveness (IOM, 2008). Although the report did not layout specific guidelines to follow, it did identify several themes that required additional attention:

- Although the incidence of CRC has declined since the 1980s, too many diagnoses are for late-stage disease and screening rates are too low.

- Messages about colorectal cancer screening are complicated by heterogeneity in testing methods and intervals at which tests are to be performed.
- Improved referral of patients from primary care providers to clinicians who directly screen for CRC would improve screening rates. (IOM, 2008)

Below are the IOM's conclusions on specific issues.

- Colorectal cancer: The incidence of colorectal cancer has declined since screening was first recommended in 1980. Even so, too many colorectal cancer diagnoses are for late-state disease, and screening rates are still too low.
- Screening tests: A fair amount of consensus exists on the current guidelines for colorectal cancer screening. However, the message is complicated by the different tests and intervals at which the tests are performed. Even though there seems to be movement toward colonoscopy as the preferred test, this is not necessarily based on evidence of better test sensitivity or specificity. Additional concerns arise as new tests are developed that provide only incremental benefit, but confuse the message to the public about colorectal cancer screening.
- Quality of screening: For colonoscopy, in particular, screening often takes place outside the primary care physician's practice. Improving the referral process so that patients are not lost would improve screening rates. Regarding the quality of the testing itself, speakers discussed variability in test results due to different readers for multiple test types and quality of bowel preparation for endoscopic screening. Nonadherence to screening guidelines results in inadequate promotion of screening or the use of non-evidence based screening tests.
- Primary care system: Primary care physicians and their staff are critical to the implementation of colorectal cancer screening. However, the primary care system is under enormous pressure. These physicians deal with significant time constraints due to a large preventive, chronic, and acute care agenda. Financial stability of the practices and incentives for preventive care in primary care practices are also important considerations.
- Workforce capacity: It is unclear whether the capacity to fully implement colorectal cancer screening is currently available. On one hand, primary care physicians do not have time to fully implement preventive care in their practices, and there may be long waits for colonoscopy appointments. On the other hand, there may be overuse of colonoscopy. The medical home concept was introduced as a possible route to address workforce issues.
- Metrics and measurements: "We often hear from community programs and organizations, which is for some advice on what we should be measuring to know whether we are getting where we want to be." Datasets such as HEDIS are helpful in addressing these concerns. Errors and quality of measurements, data standards, and reporting methods were discussed, as well as the apparent spectrum between privacy protections and transparent systems.
- Costs: Cost of screening and cost-effectiveness were common themes throughout the workshop: not only the monetary costs of the testing itself, but also the time costs of staff, particularly for small practices. Financial incentives and disincentives to physicians were also seen as affecting colorectal cancer screening implementation.
- Coverage: Colorectal cancer screening is generally covered by traditional health insurance plans and Medicare. Beyond lack of coverage for uninsured and underinsured individuals, however, "We seem to be hearing more and more about the affordability of insurance and the trend to shift more of the cost burden on the employee." This may result in lack of coverage for colonoscopy for more people. "This is at the same time we are seeing increased interest in referrals to colonoscopy." Also, a great deal of variability

in screening offerings was highlighted on a state-to-state level, among practice types, and on practice-to-practice and even physician-to-physician levels.

- Communications: The content of the message to the public was discussed, as was its place in the general preventive care agenda. Communications between health plans and providers can be improved, as can communications to providers about screening guidelines. Community- and practice-based interventions were shown to be successful, although the data focused on interventions to increase FOBT screening. Data from state and federal demonstration programs showed that large screening initiatives are useful in increasing screening rates and decreasing the incidence of colorectal cancer.
- Disparities: During the workshop, several issues of disparities were discussed, including race, gender, age, and insurance coverage. For example, African Americans experience earlier onset of colorectal cancer, suggesting that different screening guidelines might better serve this group. Another topic covered was difference between genders: depending on the setting and types of intervention, there are different screening rates and disease outcomes to be addressed.

Institute of Medicine of the National Academies. (October 2008). *Implementing Colorectal Cancer Screening. Workshop Summary*. <http://iom.edu/Reports/2008/Implementing-Colorectal-Cancer-Screening-Workshop-Summary.aspx>.

Appendix 4: Summary of IOM Standards for Developing Trustworthy Clinical Practice Guidelines

1. Establishing Transparency

- 1.1 The processes by which a CPG is developed and funded should be detailed explicitly and publicly accessible.

2. Management of Conflict of Interest (COI)

- 2.1 Prior to selection of the guideline development group (GDG), individuals being considered for membership should declare all interests and activities potentially resulting in COI with development group activity, by written disclosure to those convening the GDG:

- Disclosure should reflect all current and planned commercial (including services from which a clinician derives a substantial proportion of income), non-commercial, intellectual, institutional, and patient–public activities pertinent to the potential scope of the CPG.

- 2.2 Disclosure of COIs within GDG:

- All COI of each GDG member should be reported and discussed by the prospective development group prior to the onset of his or her work.
- Each panel member should explain how his or her COI could influence the CPG development process or specific recommendations.

2.3 Divestment

- Members of the GDG should divest themselves of financial investments they or their family members have in, and not participate in marketing activities or advisory boards of, entities whose interests could be affected by CPG recommendations.

2.4 Exclusions

- Whenever possible GDG members should not have COI.
- In some circumstances, a GDG may not be able to perform its work without members who have COIs, such as relevant clinical specialists who receive a substantial portion of their incomes from services pertinent to the CPG.
- Members with COIs should represent not more than a minority of the GDG.
- The chair or cochairs should not be a person(s) with COI.
- Funders should have no role in CPG development.

3. Guideline Development Group Composition

- 3.1 The GDG should be multidisciplinary and balanced, comprising a variety of methodological experts and clinicians, and populations expected to be affected by the CPG.
- 3.2 Patient and public involvement should be facilitated by including (at least at the time of clinical question formulation and draft CPG review) a current or former patient, and a patient advocate or patient/consumer organization representative in the GDG.
- 3.3 Strategies to increase effective participation of patient and consumer representatives, including training in appraisal of evidence, should be adopted by GDGs.

4. Clinical Practice Guideline–Systematic Review Intersection

- 4.1 Clinical practice guideline developers should use systematic reviews that meet standards set by the Institute of Medicine’s Committee on Standards for Systematic Reviews of Comparative Effectiveness Research.
- 4.2 When systematic reviews are conducted specifically to inform particular guidelines, the GDG and systematic review team should interact regarding the scope, approach, and output of both processes.

5. Establishing Evidence Foundations for and Rating Strength of Recommendations

- 5.1 For each recommendation, the following should be provided:
 - An explanation of the reasoning underlying the recommendation, including

- a clear description of potential benefits and harms;
- a summary of relevant available evidence (and evidentiary gaps), description of the quality (including applicability), quantity (including completeness), and consistency of the aggregate available evidence;
- an explanation of the part played by values, opinion, theory, and clinical experience in deriving the recommendation.
- A rating of the level of confidence in (certainty regarding) the evidence underpinning the recommendation.
- A rating of the strength of the recommendation in light of the preceding bullets.
- A description and explanation of any differences of opinion regarding the recommendation.

6. Articulation of Recommendations

- 6.1 Recommendations should be articulated in a standardized form detailing precisely what the recommended action is, and under what circumstances it should be performed.
- 6.2 Strong recommendations should be worded so that compliance with the recommendation(s) can be evaluated.

7. External Review

- 7.1 External reviewers should comprise a full spectrum of relevant stakeholders, including scientific and clinical experts, organizations (e.g., health care, specialty societies), agencies (e.g., federal government), patients, and representatives of the public.
- 7.2 The authorship of external reviews submitted by individuals and/or organizations should be kept confidential unless that protection has been waived by the reviewer(s).
- 7.3 The GDG should consider all external reviewer comments and keep a written record of the rationale for modifying or not modifying a CPG in response to reviewers' comments.
- 7.4 A draft of the CPG at the external review stage or immediately following it (i.e., prior to the final draft) should be made available to the general public for comment. Reasonable notice of impending publication should be provided to interested public stakeholders.

8. Updating

- 8.1 The CPG publication date, date of pertinent systematic evidence review, and proposed date for future CPG review should be documented in the CPG.
- 8.2 Literature should be monitored regularly following CPG publication to identify the emergence of new, potentially relevant evidence and to evaluate the continued validity of the CPG.

8.3 CPGs should be updated when new evidence suggests the need for modification of clinically important recommendations. For example, a CPG should be updated if new evidence shows that a recommended intervention causes previously unknown substantial harm; that a new intervention is significantly superior to a previously recommended intervention from an efficacy or harms perspective; or that a recommendation can be applied to new populations.

Appendix 5: Medical and Nursing Professional Societies/Organizations Identified in Initial Internet Search

Medical Organizations

- *American Academy of Family Physicians
- † American Academy of Home Care Physicians
- § American Academy of Physician Assistants
- † American Association of Public Health Physicians
- † American College of Osteopathic Family Physicians
- *American College of Physicians
- *American Congress of Obstetricians and Gynecologists
- † American Holistic Medical Association
- *American Medical Association
- *American Medical Women's Association
- *American Osteopathic Association
- † Association of American Indian Physicians
- † Association of Departments of Family Medicine
- † Association of Family Practice Physician Assistants
- † Association of Family Practice Residency Directors
- † Association of Program Directors in Internal Medicine
- † Catholic Medical Association
- † Christian Medical & Dental Associations
- † Fellowship of Christian Physician Assistants
- † National American Arab Medical Association
- † National Commission on Certification of Physician Assistants
- † National Hispanic Medical Association
- † National Medical Association
- † Physician Assistant Education Association
- † Society of Army Physician Assistants
- † Society of General Internal Medicine

Nursing Organizations

- † Alpha Tau Delta National Fraternity for Professional Nurses
- † American Academy of Ambulatory Care Nursing
- § American Academy of Nurse Practitioners
- † American Academy of Nursing
- † American Assembly for Men in Nursing
- † American College of Nurse Practitioners
- † American Holistic Nurses Association
- † American Nurses Association
- † Association of Family Practice Residency Nurses
- † Association of Women's Health, Obstetric and Neonatal Nurses
- † Gerontological Advanced Practice Nurses Association
- † National Alaska Native American Indian Nurses Association
- † National American Arab Nurses Association
- † National Association of Catholic Nurses
- † National Association of Clinical Nurse Specialists

- † National Association of Hispanic Nurses
- † National Association of Nurse Practitioners in Women's Health
- † National Black Nurses Association
- † National Coalition of Ethnic Minority Nurse Associations Inc.
- † National Gerontological Nursing Association
- † National League for Nursing Inc.
- † Nurse Practitioner Healthcare Foundation
- † Nurses Christian Fellowship
- † Nurses Organization of Veteran Affairs
- † Philippine Nurses Association of America, Inc.
- † Samoan National Nurses Association
- † Sigma Theta Tau International

* Organization met all study criteria:

- U.S.-based primary care professional society (or a professional society with a primary care segment)
- National in focus
- Addressed colorectal cancer screening issues through position statements or clinical recommendations.

† Organization was excluded from the study because it did not address colorectal cancer screening issues through position statements or clinical recommendations.

§ Organization did not address colorectal cancer screening issues through position statements or clinical recommendations, but was included in the study because it was the largest organization serving a key stakeholder community (i.e. nurse practitioners or physician assistants).

Appendix 6: Invitation Letter



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
Office of the Director
Office of Disease Prevention

Date

Dear [first and last name]:

I would like to invite you to participate in an evaluation study by the National Institutes of Health (NIH) titled: ***Moving Research Into Practice: The Diffusion of Evidence-based Recommendations Through Professional Societies***. This project is being led by the NIH Office of Disease Prevention with technical assistance provided by the NIH National Cancer Institute and the Johns Hopkins Bloomberg School of Public Health.

For this study, we are soliciting thoughtful input from approximately 30 key informants involved in different professional societies. Participants are asked to volunteer an hour of their time for a telephone interview to discuss how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations. Participants will be provided a \$60 honorarium to thank them for their time.

Your experience as a [INSERT leader in NAME OF PROFESSIONAL SOCIETY (OR) a member of NAME OF PROFESSIONAL SOCIETY] would provide valuable insights for this study. The evaluation findings will be compiled into a report for the Office of Disease Prevention and will ultimately help strengthen scientific panels at the NIH and enhance panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members. Data will also be utilized as a part of a dissertation project at the Johns Hopkins Bloomberg School of Public Health.

Enclosed you will find a description of the study, letters from the Office of Disease Prevention and the National Cancer Institute, a response card to indicate your interest in participating, consent forms (one to keep and one to sign and return if you choose to participate), and a stamped return envelope. If you have any questions, please feel free to contact me (neilsone@mail.nih.gov | 301-496-4999) or the project advisor, Dr. Barbara Cohen (barbara.cohen5@verizon.net | 301-812-7039). Thank you very much for your consideration.

Sincerely,

Elizabeth Neilson, M.S.N., M.P.H.
Principal Investigator
Senior Communications Advisor
Office of Disease Prevention
National Institutes of Health
Doctoral Candidate, Johns Hopkins Bloomberg School of Public Health

Appendix 7: Study Description

Study Description

Study Title: Moving Research Into Practice: The Diffusion of Evidence-based Recommendations Through Professional Societies

Principal Investigator: Elizabeth Neilson

What you should know about this study

- You are being asked to join a research study.
- You are a volunteer. You can choose not to take part; if you join, you may quit at any time. There will be no penalty if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.

Purpose of research project

The National Institutes of Health (NIH), Office of Disease Prevention's Consensus Development Program (CDP) convenes scientific panels yearly to assess complex medical issues and develop recommendations to increase understanding and assist health professionals and other stakeholders in decisionmaking. The purpose of this study is to explore how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations (e.g., colorectal cancer screening). The knowledge gained from this study will be used to strengthen the CDP and enhance its panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members. Data will also be utilized as part of a dissertation project at the Johns Hopkins School of Public Health.

Why you are being asked to participate

You are being asked to take part in an NIH research study because of your position or membership in a professional society. We anticipate that 30 people, involved in several professional societies, will participate in this study.

Procedures

Here is a list of what will happen if you join this study:

- You will take part in a one-time 1-hour telephone interview.
- At the beginning of the interview, you will be asked to confirm your name and provide your address. This information will be used to process an honorarium (\$60) to thank you for your time. Your name and address will be removed from the interview transcript before any data analysis.

- You will also be asked about your professional society and your role in the organization. This information will be de-identified for data analysis and presentation.
- During the interview, you will be asked about your professional society's support and dissemination of clinical recommendations (including colorectal cancer screening).
- The interview will be audio-recorded. The recording will be destroyed within 30 days of the interview, and transcripts will be stored on a password-protected server.

Risks/discomforts

There are minimal risks to you for participating. There is a possible risk of discomfort in sharing your views during the interview.

Every effort will be made to keep the information you give us private. Your name will never be linked to any comments nor will it appear in any written reports or publications. It is very unlikely that those outside the study could find out the information you provide.

Benefits

There is no direct benefit to you for being in this study, but the answers you provide may help the NIH in developing and disseminating evidence-based recommendations that are of use to professional societies and their members.

Payment

A \$60 honorarium is provided to study participants.

Protecting your privacy

The information you provide will be kept private to the furthest extent provided by law. Interview transcripts will be marked by a unique code number. Transcripts and the link between code number and identifiable information will be kept on a password-protected server. Other study information (e.g., the processing of your honorarium) will be stored in a locked filing cabinet within a secure office at NIH's study contractor—IQ Solutions, Inc.

Access to the information we collect will be limited to study analysts and people in charge of making sure the research is done correctly. This might include people from the NIH Office of Human Research Protections. All of these people are required to keep your information private.

De-identified data will be used for all analyses and presentations.

Options

You do not have to take part in this study. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits you would otherwise receive.

Cost of participation in the study

There will be no monetary cost to you for taking part in this study.

What happens if you leave the study early?

Your participation in this research study is completely voluntary. You have the right to withdraw from the research study at any time. Even if you do not want to join the study, or if you withdraw from the study, it will not affect your relationship with the NIH.

You may leave this study early if you so chose. Under some circumstances, the principal investigator or the sponsor (NIH Office of Disease Prevention) may ask you to leave the study early. In either case, there will be no consequence to you.

Whom to call if you have questions

If you have any questions about the research, please call the principal investigator, Elizabeth Neilson, at 301-496-4999 or the NIH Office of Human Subjects Research Protections (OHSRP) at 301-402-3444 or Fax 301-402-3443. (See below for address and additional information.)

Call or contact the NIH OHSRP if you have questions about your rights as a study participant. Contact information is provided below.

National Institutes of Health
Office of Human Subjects Research Protections
Building 10, Room 2C116
Bethesda, Maryland 20892-1154
Telephone: 301-402-3444
Fax: 301-402-3443
Email: ohsr_nih_ddir@od.nih.gov

Appendix 8: Letter of Support from NIH Office of Disease Prevention



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
Office of the Director
Office of Disease Prevention

[Date]



Dear [Redacted],

The National Institutes of Health (NIH), Office of Disease Prevention is conducting an evaluation of its Consensus Development Program (CDP). I sincerely hope you will participate in this project, titled **"Moving Research Into Practice: The Diffusion of Evidence-based Recommendations Through Professional Societies."**

Since 1977, the NIH has supported the Consensus Development Program, which produces unbiased, evidence-based assessments of controversial or complex medical issues to advance understanding among health professionals and the public. We believe this evaluation, which examines the role and importance of the CDP and its recommendations among clinicians and their professional societies, will strengthen the program and enhance its value to stakeholders.

If you have any questions about this evaluation, please contact our project lead, Elizabeth Neilson, ODP Senior Communications Advisor, at neilsone@mail.nih.gov | 301-496-4999 or our contracted project advisor, Dr. Barbara Cohen, at barbara.cohen5@verizon.net | 301-812-7039. Thank you very much for your consideration.

Yours truly,

A handwritten signature in black ink, appearing to read "David M. Murray", is located below the "Yours truly," text.

David M. Murray, Ph.D.
Associate Director for Prevention
Director, Office of Disease Prevention
Office of the Director
National Institutes of Health
6100 Executive Blvd. Room 2B03
Bethesda, Maryland 20892

Appendix 9: Letter of Support from NCI Division of Cancer Control and Population Sciences



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Cancer Institute

February 11, 2013

Ms. Elizabeth Neilson
Senior Communications Advisor
Office of Disease Prevention
National Institutes of Health
6100 Executive Blvd. Room 2B03
Bethesda, Maryland 20892

Dear Ms. Neilson,

I would like to express my strong support for the project, "Moving Research Into Practice: The Diffusion of Evidence-based Recommendations Through Professional Societies."

For the past 35 years, the National Cancer Institute (NCI) has been a supporter of the NIH Consensus Development Program (CDP), which produces unbiased, evidence-based assessments of controversial or complex medical issues to advance understanding among health professionals and the public. The NCI has co-sponsored 40 CDP conferences, including the conference on "Enhancing Use and Quality of Colorectal Cancer Screening."

This project—which evaluates the CDP as well as colorectal cancer screening knowledge, attitudes, and practices—will assist the National Institutes of Health in strengthening its evidence-based assessments and recommendations so they are more accessible, pertinent, and actionable for key stakeholders. The NCI is pleased to collaborate on this project by providing technical assistance on the project's interview guides and processes and by reviewing the final report.

I look forward to working with you in the coming months and helping to make this project a success.

Yours truly,

A handwritten signature in cursive script, appearing to read "Gordon Willis".

Gordon Willis, Ph.D.
Cognitive Psychologist
Applied Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute
National Institutes of Health
6130 Executive Blvd. MSC 7344
Bethesda, Maryland 20892

Appendix 10: Consent Form

INFORMED CONSENT DOCUMENT

Qualitative Interviews

Study Title: Moving Research Into Practice: The Diffusion of Evidence-based Recommendations Through Professional Societies

Principal Investigator: Elizabeth Neilson

IRB No.: 11735

PI Version Date: Version 2 / February 5, 2013

What you should know about this study

- You are being asked to join a research study.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- You are a volunteer. You can choose not to take part; if you join, you may quit at any time. There will be no penalty if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.

Purpose of research project

The National Institutes of Health (NIH), Office of Disease Prevention's Consensus Development Program (CDP) convenes scientific panels yearly to assess complex medical issues and develop recommendations to increase understanding and assist health professionals and other stakeholders in decision-making. The purpose of this study is to explore how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations (e.g., colorectal cancer screening). The knowledge gained from this study will be used to strengthen the CDP and enhance its panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members. Data will also be utilized as part of a dissertation project at the Johns Hopkins School of Public Health.

Why you are being asked to participate

You are being asked to take part in an NIH research study because of your position or membership in a professional society. We anticipate that 30 people, involved in several professional societies, will participate in this study.

Procedures

Here is a list of what will happen if you join this study:

- You will take part in a one-time 1-hour telephone interview.

- At the beginning of the interview, you will be asked to confirm your name and provide your address. This information will be used to process an honorarium (\$60) to thank you for your time. Your name and address will be removed from the interview transcript before any data analysis.
- You will also be asked about your professional society and your role in the organization. This information will be de-identified for data analysis and presentation.
- During the interview, you will be asked about your professional society's support and dissemination of clinical recommendations (including colorectal cancer screening).
- The interview will be audio-recorded. The recording will be destroyed within 30 days of the interview, and transcripts will be stored on a password-protected server.

Risks/discomforts

There are minimal risks to you for participating. There is a possible risk of discomfort in sharing your views during the interview.

Every effort will be made to keep the information you give us private. Your name will never be linked to any comments, nor will it appear in any written reports or publications. It is very unlikely that those outside the study could find out the information you provide.

Benefits

There is no direct benefit to you for being in this study, but the answers you provide may help the NIH in developing and disseminating evidence-based recommendations that are of use to professional societies and their members.

Payment

A \$60 honorarium is provided to study participants.

Protecting your privacy

The information you provide will be kept private to the furthest extent provided by law. Interview transcripts will be marked by a unique code number. Transcripts and the link between code number and identifiable information will be kept on a password-protected server. Other study information (e.g., the processing of your honorarium) will be stored in a locked filing cabinet within a secure office at NIH's study contractor—IQ Solutions, Inc.

Access to the information we collect will be limited to study analysts and people in charge of making sure the research is done correctly. This might include people from the NIH Office of Human Subjects Research Protections. These people are required to keep your information private.

De-identified data will be used for all analyses and presentations.

Options

You do not have to take part in this study. There will be no penalty if you decide not to be in the study. If you decide not to be in the study, you will not lose any benefits you would otherwise receive.

Cost of participation in the study

There will be no monetary cost to you for taking part in this study.

What happens if you leave the study early?

Your participation in this research study is completely voluntary. You have the right to withdraw from the research study at any time. Even if you do not want to join the study, or if you withdraw from the study, it will not affect your relationship with the NIH. You should ask the principal investigator listed below any questions you may have about this research study. You may ask her questions in the future if you do not understand something that is being done.

You may leave this study early if you so chose. Under some circumstances, the principal investigator or the sponsor (NIH Office of Disease Prevention) may ask you to leave the study early. In either case, there will be no consequence to you.

Whom to call if you have questions or problems

If you have any questions, concerns, or complaints about the research study, please call the principal investigator, Elizabeth Neilson, at 301–496–4999 or the NIH Office of Human Subjects Research Protections (OHSRP) at 301–402–3444 or Fax 301–402–3443. (See below for address and additional information.) Either the principal investigator or staff from OHSRP will answer your questions and/or help you find care if you feel you have suffered an injury as a result of this study. The Federal Government does not have any program to provide compensation to you if you experience injury or other bad effects which are not the fault of the investigators.

Call or contact the NIH OHSRP if you have questions about your rights as a study participant, if you feel you have not been treated fairly, or if you have other concerns.

Office of Human Subjects Research Protections
National Institutes of Health
Building 10, Room 2C116
Bethesda, Maryland 20892-1154
Telephone: 301–402–3444
Fax: 301–402–3443
Email: ohsr_nih_ddir@od.nih.gov

What does your signature on this consent form mean?

Your signature on this form means:

- You have been informed about this study’s purpose, procedures, possible benefits, and risks.
- You have been given the chance to ask questions before you sign.
- You have voluntarily agreed to be in this study.

Print Name of Adult Participant

Signature of Adult Participant

Date

Print Name of Person Obtaining
Consent

Signature of Person Obtaining Consent

Date

Please check either Yes or No before placing your signature and date below.

☐ Yes ☐ No I may be contacted in the future regarding this study, if clarification is requested
regarding a response from the interview and/or for more detailed information.

Participant's Signature

Date

One copy of this form is given to the participant. Another copy is kept for the study's records.

Appendix 11: Response Sheet

[Study #]

NIH Study Response Sheet

Study Title: Moving Research Into Practice: The Diffusion of Evidence-based Recommendations Through Professional Societies

Please check the appropriate response below and mail this form in the stamped return envelope that has been provided.

_____ Yes, I would like to participate in this research study. I am also including a signed consent form in the stamped return envelope.

_____ Yes, I am interested in participating in this research study, but I would like more information. Please contact me with additional details. I can be reached at this telephone number _____ or email address _____.

_____ No, I am not interested in participating in this research study.

_____ No, I am not interested in participating in this research study, but I have a colleague who may be interested in participating. Please contact _____ at this telephone number _____ or email address _____.

Appendix 12: Physician Leadership Interview Guide

Semi-Structured Interview with Physician Professional Society Leaders

American Academy of Family Physicians (AAFP)
American College of Physicians (ACP)
American Congress of Obstetricians and Gynecologists (ACOG)
American Medical Association (AMA)
American Medical Women's Association (AMWA)
American Osteopathic Association (AOA)

Hi. My name is _____ and I am calling to conduct an interview for the NIH Consensus Development Program study that you agreed to participate in. _____, who will be taking notes, joins me on the telephone. With your permission we would like to record the interview to assist us with our analysis. To help protect your confidentiality, we will code answers so that no responses are attributed to a particular person or organization.

The purpose of this study is to explore how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations (for example, colorectal cancer screening). The knowledge gained from this study will be used to strengthen the NIH Consensus Development Program and enhance its panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members.

You are being asked to take part in this study because of your role in a professional society. Our focus today will be on your perspective as a leader in a [INSERT PROFESSIONAL SOCIETY].

Before we start the interview, I want to be sure that I have your correct information:

Name:
Organization:
Position:
Address:

Do you have any questions before we begin?

I. Background on physician professional societies

Great. I would like to start by asking you a little about your organization.

1. Can you briefly describe the [INSERT PROFESSIONAL SOCIETY]?
PROBE for size (both members and staff), goals, organizational structure, centralization of decision-making, and the formalization of rules and regulations

II. Scientific panels and evidence-based practice and recommendations

Now I'd like to discuss evidence-based practice and evidence-based recommendations.

2. We are interested in understanding the role that primary care professional societies play in promoting evidence-based practice. So first, I would like to know how you define evidence-based practice and evidence-based recommendations.
3. Does the [INSERT PROFESSIONAL SOCIETY] have a role in promoting evidence-based recommendations and practice? If so, what is that role and how is it carried out?

Now I'd like to discuss scientific panels that develop evidence-based recommendations.

4. Are you familiar with organizations or scientific panels that assess clinical issues and/or develop recommendations? If so, what do you know about them? (*If not, skip to section IV.*)

PROBE for non-profit groups (e.g., Institute of Medicine, Cochrane Collaboration), disease specialty societies (e.g., American Cancer Society), and other professional societies (e.g., American College of Radiology)

5. Is a scientific panel's organizational affiliation important to the [INSERT PROFESSIONAL SOCIETY]? If so, how?

PROBE the USPSTF as an independent scientific panel supported by the federal Agency for Healthcare Research and Quality (AHRQ) and the U.S. Multi-Society Task Force on Colorectal Cancer as a group of medical specialty societies (i.e., American Gastroenterological Association, American College of Gastroenterology, American Society for Gastrointestinal Endoscopy)

6. What makes you trust or distrust a scientific panel? Are there specific panels you trust or distrust?
7. Scientific panels vary in their composition and methods. Do the following influence your views about their recommendations?
 - a. Source of funding
 - b. Composition of panel members - **PROBE** expert, multidisciplinary, lay or patient perspectives
 - c. Reporting of member conflicts of interest – **PROBE** financial or intellectual interests
 - d. Methods used to analyze evidence – **PROBE** expert opinion, systematic review
 - e. Methods of validating panel recommendations – **PROBE** external review, internal review
8. Are the needs of your organization for clinical assessments and recommendations being met by external scientific panels? If so, how? If not, what needs are not being met?

Now I'd like to focus specifically on colorectal cancer screening recommendations.

I reviewed the [INSERT PROFESSIONAL SOCIETY] website and it appears your organization:

- a. *[For American Academy of Family Physicians] supports colorectal cancer screening recommendations developed by the U.S. Preventive Services Task Force.*
 - b. *[For American College of Physicians] published a guidance statement in 2012 that supports colorectal cancer screening recommendations developed by the U.S. Preventive Services Task Force.*
 - c. *[For American Congress of Obstetricians and Gynecologists] posted an opinion that supports joint colorectal cancer screening recommendations developed by the American Cancer Society, the U.S. Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology.*
 - d. *[For American Medical Association] supports the general recommendations of “major healthcare organizations” and are consistent with the recommendations developed by the American Cancer Society, the U.S. Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology.*
 - e. *[For American Medical Women’s Association] has a position paper that supports colorectal cancer screening recommendations developed by the American Cancer Society.*
 - f. *[For American Osteopathic Association] has a 2011 Policy Compendium that supports colorectal cancer screening reimbursement based on American Cancer Society recommendations.*
9. What do you know about the [INSERT ORGANIZATION OR PANEL NAME] and how they develop recommendations?
 10. Do you trust or distrust [INSERT ORGANIZATION OR PANEL NAME]? What makes you trust or distrust them?
 11. Do you have anything else to add about scientific panels and their recommendations?

III. Professional societies’ support and dissemination of recommendations.

Now let’s focus on how the [INSERT PROFESSIONAL SOCIETY] chooses to support and disseminate clinical recommendations.

12. How does the [INSERT PROFESSIONAL SOCIETY] decide which clinical topics and issues to address?

PROBE who makes decisions, if steps are taken to get buy-in throughout leadership, if organizational characteristics are influential

13. How does the [INSERT PROFESSIONAL SOCIETY] choose which recommendations to support on a particular issue?

PROBE who makes decisions, if steps are taken to get buy-in throughout leadership, if organizational characteristics are influential

14. When deciding on which recommendations to support, how do the following issues impact your decisions?
 - a. Insurance coverage for an intervention
 - b. Patient access to an intervention
 - c. Patient attitudes and compliance

- d. Encouragement of shared decision-making between provider and patient
 - e. Implementation costs for providers
 - f. Provider preferences
 - g. Whether a recommendation is controversial
 - h. Other factors
15. When various panels issue different recommendations, how does the [INSERT PROFESSIONAL SOCIETY] reconcile the differences and choose which recommendation to support?
 16. Does the [INSERT PROFESSIONAL SOCIETY] have a relationship with [INSERT PANEL] or other external recommendation developers? If so, can you describe the nature of these relationships and how they are developed and sustained?
 17. Would you characterize your organization as being a trail blazer when supporting recommendations, or do you generally wait for other organizations to go first?
 18. How does the [INSERT PROFESSIONAL SOCIETY] disseminate information about recommendations to its members?
- PROBE** for newsletters, published statements, journal articles, presentations at annual meetings, online CME courses)

IV. Developing recommendations

19. Does the [INSERT PROFESSIONAL SOCIETY] ever develop their own clinical recommendations? (*If not, skip to **section V**; if yes, continue*)
 - a. What processes are in place to identify problems or needs?
 - b. To research solutions?
 - c. To construct a recommendation?

V. The NIH Consensus Development Program's (and the Federal government's) contribution to evidence-based practice.

The remaining questions focus on the NIH Consensus Development Program and the federal government's role in developing and disseminating recommendations.

20. Have you heard of the NIH Consensus Development Program or other federally supported recommendation developers? If yes, what do you know about them? (*If not, skip to **question 23***)

PROBE for USPSTF, CDC Preventive Services Task Force

21. Have you or someone representing your organization ever received a panel statement from the NIH Consensus Development Program? Do you routinely get their statements?
22. Have you or someone representing your organization ever attended a Consensus Development Conference or viewed one on videocast? Do you do so frequently?

23. Are there any specific characteristics of the NIH Consensus Development Program or other federally supported recommendation developers that make them uniquely trustworthy or untrustworthy sources? If so, what are they?

PROBE for panel composition, funding sources, financial/intellectual conflicts, transparency, methods of analysis, and validation of recommendations

24. In what ways could the NIH Consensus Development Program and other federally supported recommendation developers enhance their credibility with professional societies and providers?
25. What steps should be taken to make recommendations more pertinent and usable for providers and professional societies?
26. In what ways could federally-supported panels better partner with stakeholders (such as professional societies, Congress and payers) to develop and disseminate their assessments and recommendations?

Thank you for your time. Do you have any additional comments? Thanks again.

Appendix 13: Physician Membership Interview Guide

Semi-Structured Interview with Physician Society Members

American Academy of Family Physicians (AAFP)
American College of Physicians (ACP)
American Congress of Obstetricians and Gynecologists (ACOG)
American Medical Association (AMA)
American Medical Women's Association (AMWA)
American Osteopathic Association (AOA)

Hi. My name is _____ and I am calling to conduct an interview for the NIH Consensus Development Program study that you agreed to participate in. _____, who will be taking notes, joins me on the telephone. With your permission we would like to record the interview to assist us with our analysis. To help protect your confidentiality, we will code answers so that no responses are attributed to a particular person or organization.

The purpose of this study is to explore how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations (for example, colorectal cancer screening). The knowledge gained from this study will be used to strengthen the NIH Consensus Development Program and enhance its panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members.

You are being asked to take part in this study because of your membership in a professional society. Our focus today will be on your perspective as a physician and member of the [INSERT PROFESSIONAL SOCIETY].

Before we start the interview, I want to be sure that I have your correct information:

Name:

Address:

Gender:

Membership in Professional Societies:

Years Serving as a Physician:

Type of Physician:

Type of Practice: **PROBE** for solo practice, group practice, HMO, teaching hospital

Role in Practice: **PROBE** for academician/researcher, administrator, practitioner

Do you have any questions before we begin?

I. Gaining knowledge and communication preferences

Great. I'd like to start with questions about how you, as a physician, gather and learn new clinical information.

1. How are you usually exposed to new medical ideas or clinical recommendations?
2. How do you prefer to learn about new medical ideas or clinical recommendations?

PROBE for reading, attending conferences, interactive media, one-to-one learning with trained individuals

3. How do you receive information from [INSERT PROFESSIONAL SOCIETY]?
4. Do you read the [INSERT PROFESSIONAL SOCIETY]'s journal or newsletters, or participate in its annual meetings, scientific forums, and CME activities? If so, which ones?

PROBE for

- g. *[For American Academy of Family Physicians] Annals of Family Medicine, American Family Physician, Family Practice Management, and FP Essentials*
- h. *[For American College of Physicians] Annals of Internal Medicine, ACP Internist, and ACP Hospitalist*
- i. *[For American Congress of Obstetricians and Gynecologists] Green Journal (aka, Obstetrics & Gynecology)*
- j. *[For American Medical Association] Journal of the American Medical Association, Archives of Internal Medicine, and American Medical News*
- k. *[For American Medical Women's Association] bi-weekly Newsflash and quarterly newsletter*
- l. *[For American Osteopathic Association] Journal of the American Osteopathic Association, The DO, and AOA Health Watch*

5. Do you see the [INSERT PROFESSIONAL SOCIETY] as a trusted source for information?
6. Are you satisfied with the clinical information you receive from [INSERT PROFESSIONAL SOCIETY]? If so, how? If not, what aspects are you dissatisfied with?

II. Knowledge and beliefs about scientific panels and evidence-based practice and recommendations

Now I'd like to discuss evidence-based practice and evidence-based recommendations.

7. We are interested in understanding the role that physicians play in providing evidence-based care. So first, I would like to know how you define evidence-based practice.

PROBE for research evidence, expert opinion of others, personal experience, patient values and circumstances

8. How do you define evidence-based recommendations? Can you describe how evidence-based recommendations are generally developed?
9. Is it important to you that your work be guided by evidence-based information? If so, how?

Now I'd like to discuss scientific panels that develop evidence-based recommendations.

10. Are you familiar with organizations or scientific panels that assess clinical issues and/or develop recommendations? If so, what do you know about them? (*If not, skip to **section III.***)

PROBE for non-profit groups (e.g., Institute of Medicine, Cochrane Collaboration), disease specialty societies (e.g., American Cancer Society), and other professional societies (e.g., American College of Radiology)

11. What makes you trust or distrust a scientific panel? Are there specific panels you trust or distrust?

12. Is a scientific panel's organizational affiliation important to you? If so, how?

PROBE the USPSTF as an independent scientific panel supported by the federal Agency for Healthcare Research and Quality (AHRQ) and the U.S. Multi-Society Task Force on Colorectal Cancer as a group of medical specialty societies (i.e., American Gastroenterological Association, American College of Gastroenterology, American Society for Gastrointestinal Endoscopy)

13. Scientific panels vary in their composition and methods. Do the following influence your views about their recommendations?

- a. Source of funding
- b. Composition of panel members - **PROBE** expert, multidisciplinary, lay or patient perspectives – which are credible
- c. Reporting of member conflicts of interest – **PROBE** financial or intellectual interests
- d. Methods used to analyze evidence – **PROBE** expert opinion, systematic review
- e. Methods of validating panel recommendations – **PROBE** external review, internal review

14. What other factors increase or decrease a scientific panel's credibility?

15. Do you believe that clinical recommendations enhance professional practice and satisfaction or impede it? How? Do clinical recommendations affect your professional autonomy? If so, how?

16. Healthcare recommendations can affect groups differently. What are the benefits and drawbacks of following clinical recommendations for the following groups?

- Patients
- Physicians
- Health care delivery organizations and their administrators (hospitals, clinics)
- Insurance Companies
- Researchers

17. How do you feel about the large number of clinical recommendations that are developed each year?

Now I'd like to focus specifically on colorectal cancer screening recommendations.

I reviewed the [INSERT PROFESSIONAL SOCIETY] website and it appears your organization:

- a. [For American Academy of Family Physicians] supports colorectal cancer screening recommendations developed by the U.S. Preventive Services Task Force.*
- b. [For American College of Physicians] published a guidance statement in 2012 that supports colorectal cancer screening recommendations developed by the U.S. Preventive Services Task Force.*
- c. [For American Congress of Obstetricians and Gynecologists] posted an opinion that supports joint colorectal cancer screening recommendations developed by the American Cancer Society, the U.S. Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology.*
- d. [For American Medical Association] supports the general recommendations of “major healthcare organizations” and are consistent with the recommendations developed by the American Cancer Society, the U.S. Multi-Society Task Force on Colorectal Cancer, and the American College of Radiology.*
- e. [For American Medical Women’s Association] has a position paper that supports colorectal cancer screening recommendations developed by the American Cancer Society.*
- f. [For American Osteopathic Association] has a 2011 Policy Compendium that supports colorectal cancer screening reimbursement based on American Cancer Society recommendations.*

- 18. What do you know about the [INSERT ORGANIZATION OR PANEL NAME] and how they develop recommendations?
- 19. Do you trust or distrust [INSERT ORGANIZATION OR PANEL NAME]? What makes you trust or distrust them?
- 20. Do you have anything else to add about scientific panels and their recommendations?

III. Use of evidence-based recommendations.

- 21. Do you follow clinical recommendations when caring for patients? What influences your decision to follow [or not follow] recommendations? (*If not, skip to **section IV.***)
- 22. In general, what clinical recommendations do you support and/or follow? Are there specific cancer screening recommendations you follow? What factors led you to support these recommendations?

PROBE for professional society recommendations, workplace guidelines, and other tools (DynaMed, Up-to-Date)

PROBE for CRC, breast, and prostate cancer screening

- 23. Do you ever receive conflicting recommendations? If so, how do decide which recommendation to follow?
- 24. Do you have opportunities to try new recommendations on a probationary basis? If yes, please explain the circumstances around doing so.

25. When deciding on which recommendations to support, how do the following issues influence clinical decision-making and your ability to implement recommendations?
 - a. Patient insurance coverage for an intervention
 - b. Patient access to an intervention (availability of specialists or equipment)
 - c. Patient knowledge, attitudes and preferences
 - d. Patient compliance
 - e. Your preferences
 - f. Your implementation costs
 - g. Your resources (electronic health records, built-in reminder systems)
 - h. Whether a recommendation is controversial
 - i. Other factors
26. Are you able to influence any of these factors? If so, how?
27. Is shared decision-making with patients a part of your practice? If so, how do you balance shared decisionmaking on one hand, and the following of explicit recommendations on the other?
28. When thinking of your professional characteristics, would you characterize yourself as a trailblazer when supporting and following recommendations, or do you generally wait for other providers to go first?

IV. The NIH Consensus Development Program's (and the federal government's) contribution to evidence-based practice.

The remaining questions focus on the NIH Consensus Development Program and the Federal Government's role in developing and disseminating recommendations.

29. Have you heard of the NIH Consensus Development Program or other federally supported recommendation developers? What do you know about them? *(If not, skip to question 32.)*

PROBE for USPSTF, CDC Preventive Services Task Force

30. Have you ever received a panel statement from the NIH Consensus Development Program? Do you routinely get their statements?
31. Have you ever attended a Consensus Development Conference or viewed one on videocast? Do you do so frequently?
32. Do you consider the NIH Consensus Development Program, or other federally supported recommendation developers, a trustworthy or untrustworthy source? If so, what factors influence this opinion?

PROBE for panel composition, funding sources, financial/intellectual conflicts, transparency, methods of analysis, and validation of recommendations

33. In what ways could the NIH Consensus Development Program and other federally supported recommendation developers enhance their credibility with physicians?

34. What steps should be taken to make recommendations more pertinent and usable for physicians?
35. In what ways could federally-supported panels better partner with stakeholders (such as patients, professional societies, Congress and payers) to develop and disseminate their assessments and recommendations?

Thank you for your time. Do you have any additional comments? Thanks again.

Appendix 14: Nurse Practitioner/Physician Assistant Leadership Interview Guide

Semi-Structured Interview with Physician Assistant and Nurse Practitioner Professional Society Leaders

American Academy of Physician Assistants (AAPA)

American Academy of Nurse Practitioners (AANP)

Hi. My name is _____ and I am calling to conduct an interview for the NIH Consensus Development Program study that you agreed to participate in. _____, who will be taking notes, joins me on the telephone. With your permission we would like to record the interview to assist us with our analysis. To help protect your confidentiality, we will code answers so that no responses are attributed to a particular person or organization.

The purpose of this study is to explore how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations (for example, colorectal cancer screening). The knowledge gained from this study will be used to strengthen the NIH Consensus Development Program and enhance its panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members.

You are being asked to take part in this study because of your role in a professional society. Our focus today will be on your perspective as a leader in a [INSERT PROFESSIONAL SOCIETY].

Before we start the interview, I want to be sure that I have your correct information:

Name:

Organization:

Position:

Address:

Do you have any questions before we begin?

I. Background on professional societies

Great. I would like to start by asking you a little about your organization.

4. Can you briefly describe the [INSERT PROFESSIONAL SOCIETY]?

PROBE for size (both members and staff), goals, organizational structure, centralization of decision-making, and the formalization of rules and regulations

II. Scientific panels and evidence-based practice and recommendations

Now I'd like to discuss evidence-based practice and evidence-based recommendations.

5. We are interested in understanding the role that professional societies play in promoting evidence-based practice. So first, I would like to know how you define evidence-based practice and evidence-based recommendations.

6. Does the [INSERT PROFESSIONAL SOCIETY] have a role in promoting evidence-based recommendations and practice? If so, what is that role and how is it carried out?

Now I'd like to discuss scientific panels that develop evidence-based recommendations.

4. Are you familiar with organizations or scientific panels that assess clinical issues and/or develop recommendations? If so, what do you know about them? (*If not, skip to section IV.*)

PROBE for non-profit groups (e.g., Institute of Medicine, Cochrane Collaboration), disease specialty societies (e.g., American Cancer Society), and other professional societies (e.g., American College of Radiology)

5. Does the [INSERT PROFESSIONAL SOCIETY] consider and/or support recommendations from external scientific panels? If so, which ones and how? (*If not, skip to section IV.*)

PROBE for recommendations on colorectal cancer screening

6. Is a scientific panel's organizational affiliation important to the [INSERT PROFESSIONAL SOCIETY]? If so, how?

PROBE the USPSTF as an independent scientific panel supported by the federal Agency for Healthcare Research and Quality (AHRQ) and the U.S. Multi-Society Task Force on Colorectal Cancer as a group of medical specialty societies (i.e., American Gastroenterological Association, American College of Gastroenterology, American Society for Gastrointestinal Endoscopy)

7. What makes you trust or distrust a scientific panel? Are there specific panels you trust or distrust?
8. Scientific panels vary in their composition and methods. Do the following influence your views about their recommendations?
 - a. Source of funding
 - b. Composition of panel members - **PROBE** expert, multidisciplinary, lay or patient perspectives
 - c. Reporting of member conflicts of interest – **PROBE** financial or intellectual interests
 - d. Methods used to analyze evidence – **PROBE** expert opinion, systematic review
 - e. Methods of validating panel recommendations – **PROBE** external review, internal review
9. Are the needs of your organization for clinical assessments and recommendations being met by external scientific panels? If so, how? If not, what needs are not being met?
10. Do you have anything to add about scientific panels and their recommendations?

III. Professional societies' support and dissemination of recommendations.

Now let's focus on how the [INSERT PROFESSIONAL SOCIETY] chooses to support and disseminate clinical recommendations.

11. How does the [INSERT PROFESSIONAL SOCIETY] decide which clinical topics and issues to address?

PROBE who makes decisions, if steps are taken to get buy-in throughout leadership, if organizational characteristics are influential

12. How does the [INSERT PROFESSIONAL SOCIETY] choose which recommendations to support on a particular issue?

PROBE who makes decisions, if steps are taken to get buy-in throughout leadership, if organizational characteristics are influential

13. When deciding on which recommendations to support, how do the following issues impact your decisions?

- a. Insurance coverage for an intervention
- b. Patient access to an intervention
- c. Patient attitudes and compliance
- d. Encouragement of shared decision-making between provider and patient
- e. Implementation costs for providers
- f. Provider preferences
- g. Whether a recommendation is controversial
- h. Other factors

14. When various panels issue different recommendations, how does the [INSERT PROFESSIONAL SOCIETY] reconcile the differences and choose which recommendation to support?

15. Does the [INSERT PROFESSIONAL SOCIETY] have a relationship with [INSERT PANEL] or other external recommendation developers? If so, can you describe the nature of these relationships and how they are developed and sustained?

16. Would you characterize your organization as being a trail blazer when supporting recommendations, or do you generally wait for other organizations to go first?

17. How does the [INSERT PROFESSIONAL SOCIETY] disseminate information about recommendations to its members?

PROBE for newsletters, published statements, journal articles, presentations at annual meetings, online CME courses)

IV. Developing recommendations

18. Does the [INSERT PROFESSIONAL SOCIETY] ever develop their own clinical recommendations? (*If not, skip to **section V**; if yes, continue*)

- d. What processes are in place to identify problems or needs?

- e. To research solutions?
- f. To construct a recommendation?

V. The NIH Consensus Development Program's (and the Federal government's) contribution to evidence-based practice.

The remaining questions focus on the NIH Consensus Development Program and the federal government's role in developing and disseminating recommendations.

19. Have you heard of the NIH Consensus Development Program or other federally supported recommendation developers? If yes, what do you know about them? *(If not, skip to **question 23**)*

PROBE for USPSTF, CDC Preventive Services Task Force

20. Have you or someone representing your organization ever received a panel statement from the NIH Consensus Development Program? Do you routinely get their statements?
21. Have you or someone representing your organization ever attended a Consensus Development Conference or viewed one on videocast? Do you do so frequently?
22. Are there any specific characteristics of the NIH Consensus Development Program or other federally supported recommendation developers that make them uniquely trustworthy or untrustworthy sources? If so, what are they?

PROBE for panel composition, funding sources, financial/intellectual conflicts, transparency, methods of analysis, and validation of recommendations

23. In what ways could the NIH Consensus Development Program and other federally supported recommendation developers enhance their credibility with professional societies and providers?
24. What steps should be taken to make recommendations more pertinent and usable for providers and professional societies?
25. In what ways could federally-supported panels better partner with stakeholders (such as professional societies, Congress and payers) to develop and disseminate their assessments and recommendations?

Thank you for your time. Do you have any additional comments? Thanks again.

Appendix 15: Nurse Practitioner/Physician Assistant Membership Interview Guide

Semi-Structured Interview with Physician Assistant & Nurse Practitioner Society Members

American Academy of Physician Assistants (AAPA)

American Academy of Nurse Practitioners (AANP)

Hi. My name is _____ and I am calling to conduct an interview for the NIH Consensus Development Program study that you agreed to participate in. _____, who will be taking notes, joins me on the telephone. With your permission we would like to record the interview to assist us with our analysis. To help protect your confidentiality, we will code answers so that no responses are attributed to a particular person or organization.

The purpose of this study is to explore how professional societies (and their members) view scientific panels and disseminate or implement evidence-based recommendations (for example, colorectal cancer screening). The knowledge gained from this study will be used to strengthen the NIH Consensus Development Program and enhance its panel recommendations so they are more accessible, pertinent, and actionable for professional societies and their members.

You are being asked to take part in this study because of your membership in a professional society. Our focus today will be on your perspective as a [INSERT PHYSICIAN ASSISTANT OR NURSE PRACTITIONER] and member of the [INSERT PROFESSIONAL SOCIETY].

Before we start the interview, I want to be sure that I have your correct information:

Name:

Address:

Gender:

Membership in Professional Societies:

Years Serving as a [INSERT PHYSICIAN ASSISTANT OR NURSE PRACTITIONER]:

Area of Specialty:

Type of Practice: **PROBE** for group practice, HMO, teaching hospital

Role in Practice: **PROBE** for academician/researcher, administrator, practitioner

Do you have any questions before we begin?

III. Gaining knowledge and communication preferences

Great. I'd like to start with questions about how you gather and learn new clinical information.

11. How are you usually exposed to new clinical ideas or recommendations?

12. How do you prefer to learn about new clinical ideas and recommendations?

PROBE for reading, attending conferences, interactive media, one-to-one learning with trained individuals

13. How do you receive information from [INSERT PROFESSIONAL SOCIETY]?

14. Do you read the [INSERT PROFESSIONAL SOCIETY]'s journal or newsletters, or participate in its annual meetings, scientific forums, and CME activities? If so, which ones?

PROBE for

- m. *[For American Academy of Physician Assistants] Journal of the American Academy of Physician Assistants, PA Professional, PA Pro Now*
- n. *[For American Academy of Nurse Practitioners] Journal of the American Academy of Nurse Practitioners, AANP SmartBrief*

15. Do you see the [INSERT PROFESSIONAL SOCIETY] as a trusted source for information?
16. Are you satisfied with the clinical information you receive from [INSERT PROFESSIONAL SOCIETY]? If so, how? If not, what aspects are you dissatisfied with?

IV. Knowledge and beliefs about scientific panels and evidence-based practice and recommendations

Now I'd like to discuss evidence-based practice and evidence-based recommendations.

17. We are interested in understanding the role that [INSERT PHYSICIAN ASSISTANTS OR NURSE PRACTITIONERS] play in providing evidence-based care. So first, I would like to know how you define evidence-based practice.

PROBE for research evidence, expert opinion of others, personal experience, patient values and circumstances

18. How do you define evidence-based recommendations? Can you describe how evidence-based recommendations are generally developed?
19. Is it important to you that your work be guided by evidence-based information? If so, how?

Now I'd like to discuss scientific panels that develop evidence-based recommendations.

20. Many organizations have scientific panels that assess clinical issues and/or develop recommendations. Are you familiar with any? If so, what do you know about them? (*If not, skip to section III.*)

PROBE for federally-supported panels (e.g., USPSTF), non-profit groups (e.g., Institute of Medicine, Cochrane Collaboration), disease specialty societies (e.g., American Cancer Society), and professional societies (e.g., U.S. Multi-Society Task Force on Colorectal Cancer, American College of Radiology)

21. What makes you trust or distrust a scientific panel? Are there specific panels you trust or distrust?

22. Is a scientific panel's organizational affiliation important to you? If so, how?

PROBE the USPSTF as an independent scientific panel supported by the federal Agency for Healthcare Research and Quality (AHRQ) and the U.S. Multi-Society Task Force on Colorectal Cancer as a group of medical specialty societies (i.e., American Gastroenterological Association, American College of Gastroenterology, American Society for Gastrointestinal Endoscopy)

23. Scientific panels vary in their composition and methods. Do the following influence your views about their recommendations?

- a. Source of funding
- b. Composition of panel members - **PROBE** expert, multidisciplinary, lay or patient perspectives – which are credible
- c. Reporting of member conflicts of interest – **PROBE** financial or intellectual interests
- d. Methods used to analyze evidence – **PROBE** expert opinion, systematic review
- e. Methods of validating panel recommendations – **PROBE** external review, internal review

24. What other factors increase or decrease a scientific panel's credibility?

25. Do you believe that clinical recommendations enhance professional practice and satisfaction or impede it? How? Do clinical recommendations affect your professional autonomy? If so, how?

26. Healthcare recommendations can affect groups differently. What are the benefits and drawbacks of following clinical recommendations for the following groups?

- Patients
- Physicians
- Health care delivery organizations and their administrators (hospitals, clinics)
- Insurance Companies
- Researchers

27. How do you feel about the large number of clinical recommendations that are developed each year?

28. Are you aware of policy statements, recommendations, or guidelines that the [INSERT PROFESSIONAL SOCIETY] supports? If yes, are you aware of how they are developed?

III. Use of evidence-based recommendations.

29. Do you follow clinical recommendations when caring for patients? What influences your decision to follow [or not follow] recommendations? (*If not, skip to **section IV**.*)

30. In general, what clinical recommendations do you support and/or follow? Are there specific cancer screening recommendations you follow? What factors led you to support these recommendations?

PROBE for professional society recommendations, workplace guidelines, and other tools (DynaMed, Up-to-Date)

PROBE for CRC, breast, and prostate cancer screening

31. Do you ever receive conflicting recommendations? If so, how do decide which recommendation to follow?
32. Do you have opportunities to try new recommendations on a probationary basis? If yes, please explain the circumstances around doing so.
33. When deciding on which recommendations to support, how do the following issues influence clinical decision-making and your ability to implement recommendations?
 - a. Patient insurance coverage for an intervention
 - b. Patient access to an intervention (availability of specialists or equipment)
 - c. Patient knowledge, attitudes and preferences
 - d. Patient compliance
 - e. Your preferences
 - f. Your implementation costs
 - g. Your resources (electronic health records, built-in reminder systems)
 - h. Whether a recommendation is controversial
 - i. Other factors
34. Are you able to influence any of these factors? If so, how?
35. Is shared decision-making with patients a part of your practice? If so, how do you balance shared decisionmaking on one hand, and the following of explicit recommendations on the other?
36. When thinking of your professional characteristics, would you characterize yourself as a trailblazer when supporting and following recommendations, or do you generally wait for other providers to go first?

IV. The NIH Consensus Development Program's (and the federal government's) contribution to evidence-based practice.

The remaining questions focus on the NIH Consensus Development Program and the Federal Government's role in developing and disseminating recommendations.

37. Have you heard of the NIH Consensus Development Program or other federally supported recommendation developers? What do you know about them?
(If not, skip to **question 31.**)

PROBE for USPSTF, CDC Preventive Services Task Force

38. Have you ever received a panel statement from the NIH Consensus Development Program? Do you routinely get their statements?
39. Have you ever attended a Consensus Development Conference or viewed one on videocast? Do you do so frequently?

40. Do you consider the NIH Consensus Development Program, or other federally supported recommendation developers, a trustworthy or untrustworthy source? If so, what factors influence this opinion?

PROBE for panel composition, funding sources, financial/intellectual conflicts, transparency, methods of analysis, and validation of recommendations

41. In what ways could the NIH Consensus Development Program and other federally supported recommendation developers enhance their credibility with [INSERT PHYSICIAN ASSISTANTS OR NURSE PRACTITIONERS]?
42. What steps should be taken to make recommendations more pertinent and usable for [INSERT PHYSICIAN ASSISTANTS OR NURSE PRACTITIONERS]?
43. In what ways could federally-supported panels better partner with stakeholders (such as patients, professional societies, Congress and payers) to develop and disseminate their assessments and recommendations?

Thank you for your time. Do you have any additional comments? Thanks again.

Appendix 16: Codebook

List of Codes

1. **Eb** Evidence-based Practice, Assessments, and Recommendations
2. **Know** Knowledge of Organizations and Scientific Panels
3. **Att** Attitudes and Beliefs about Organizations and Scientific Panels
4. **PrUt** Provider Utilization of Panel Outputs
5. **InO** Innovation in Organizations
6. **Value** Value Federal Government Contributes to Evidence-based Practice by Developing and Disseminating Assessments and recommendations
7. **Sugg** Suggestions for Federally-Sponsored Panels to Consider for the Development of More Trustworthy, Feasible, and Pertinent Outputs
8. **Feed** Feedback on this study

Eb Evidence-based Practice, Assessments, & Recommendations

Eb-P Evidence-based Practice

Eb-Out Evidence-based Outputs

Know Knowledge of Organizations and Scientific Panels

Know-A Awareness of Organizations and Scientific Panels

Know-U Understanding of Organization and Panel Composition, Processes, & Outputs

Know-U/Back Background of Members

Know-U/Fund Source of Panel Funding

Know-U/Ana Compiling & Analyzing Evidence

Know-U/Form Methods Used to Formulate Assessments & Recommendations

Know-U/Rec Assessments & Recommendations

Know-U/Rev Review of Assessments & Recommendations

Know-U/Het Heterogeneity

Att Attitudes and Beliefs about Organizations and Scientific Panels

Att-TM Trust and Mistrust of Organizations and Scientific Panels

Att-TM/Cred Credibility of Composition, Processes, & Outputs

Att-TM/Cred/COI Promoting Objectivity and Effective Panel Composition While Managing Conflict of Interest

Att-TM/Cred/Rig Methodological Rigor

Att-TM/Cred/Tran Transparency

Att-TM/Cred/Het Heterogeneity

Att-TM/FP Feasibility & Pertinence of Outputs

Att-TM/FP/Care General Population vs. Unique, Individualized Care

Att-BD Benefits and Drawbacks of Outputs

- Att-BD/High** High Volume of Outputs and Information Overload
- Att-BD/IPP** Impact on Professional Practice
 - Att-BD/IPP/Sat** Satisfaction
 - Att-BD/IPP/Cont** Professional Control
 - ATT-BD/IPP/Cont/Auto** Tension between Outputs and Autonomy
 - ATT-BD/IPP/Cont/Ten** Tension between Elite, and Rank and File
 - ATT-BD/IPP/Cont/PCvS** Tension between Specialists and Primary Care Providers
 - Att-BD/IPP/Qual** Quality of Care

Att-Meet Meeting Professional Society and Health Care Provider Needs for Evidence-based Outputs

- Att-Meet/CFP** Availability of Trustworthy, Feasible, & Pertinent Outputs

PrUt Provider Utilization of Panel Outputs

- PrUt-Use** Use of Outputs
- PrUt-Het** Heterogeneity
- PrUt-Fact** Factors Associated with Utilization of Services
 - PrUt-Fact/Sys** Healthcare System
 - PrUt-Fact/EE** External Environment
 - PrUt-Fact/PCh** Predisposing Characteristics
 - PrUt-Fact/ER** Enabling Resources
 - PrUt-Fact/Need** Need
 - PrUt-Fact/HB** Health Behavior
- PrUt-Inf** Provider Influence over Utilization Factors

InO Innovation in Organizations

- InO-PR** Innovation Process for Organizations
 - InO-PR/Ini** Initiation
 - InO-PR/Ini/AS** Agenda Setting
 - InO-PR/Ini/Mat** Matching
 - InO-PR/Imp** Implementation
 - InO-PR/Imp/Rout** Routinizing/Dissemination Though Communication Channels
 - InO-PR/Imp/Rout/External** Non-Organizational Channels of Information for Members
 - InO-PR/Imp/Rout/Pref** Members' Preferred Channels of Communication
 - InO-PR/Imp/Rout/Sat** Member Satisfaction with Dissemination
- InO-Ch** Organizational Background & Characteristics

InO-Ch/Over History/Mission
InO-Ch/Cent Centralization
InO-Ch/Comp Complexity
InO-Ch/Formal Formalization
InO-Ch/Inter Interconnectedness
InO-Ch/Size Size
InO-Ch/Open System Openness
InO-RIn Perceived Relative Innovativeness

Value Value Federal Government Contributes to Evidence-based Practice by Developing & Disseminating Assessments & Recommendations

Value-Tran Transparency
Value-Obj Objectivity
Value-Rig Methodological Rigor

Sugg Suggestions for Federally-Sponsored Panels to Consider for the Development of More Trustworthy, Feasible, & Pertinent Outputs

Sugg-TW Trustworthy Assessments & Recommendations
Sugg-Pert Pertinent Assessments & Recommendations
Sugg-Feas Feasible Recommendations

Feed Feedback on Study

Codes & Definitions

Eb Evidence-based Practice, Assessments, & Recommendations

Eb-P Evidence-based Practice

Evidence-based practice (EBP) means different things to different people; therefore, a variety of responses are expected. We view EBP as an integration of the best research evidence with clinical expertise and the patient's unique values and circumstances. Best research evidence is clinically relevant research that has been critically appraised and found to be the finest in scientific merit. By clinical expertise, we mean the ability to use our clinical skills and past experience to rapidly identify each patient's unique health state and diagnosis, their individual risks and benefits of potential interventions, and their personal values and expectations. By patient values we mean the unique preferences, concerns, and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions if they are to serve the patient. By patient circumstances we mean their individual state and the clinical setting. This code also covers discussions of “standards of care” and if these are based on evidence or other factors.

Eb-Out Evidence-based Outputs

Assessments and recommendations informing decision-makers, which are based on “rigorous, comprehensive syntheses and analyses of the scientific literature” and is accompanied by “explicit and detailed documentation of methods, rationale, and assumptions.”

Know Knowledge of Organizations and Scientific Panels

When an individual or professional society learns of a panel's or organization's existence and gains some understanding of its structure, how it functions, and its outputs.

Know-A Awareness of Organizations and Scientific Panels

When an individual or professional society learns of a panel's or organization's existence.

Know-U Understanding of Organization and Panel Composition, Process, & Outputs

When an individual or professional society comprehends the function, structure, processes, and outputs of a panel. Understanding often occurs as a result of direct experience (e.g., attending a panel meeting, reviewing panel statements, etc.)

Know-U/Back Background of Members

Refers to the professionals serving as members of the scientific panel or organization (examples include methodologists, clinicians with experience in prevention and primary care [family medicine, internal medicine, nursing, obstetrics/gynecology, pediatrics, and behavioral medicine]; clinical subspecialists, those with experience in relevant field [policymakers, payers, ethicists], and consumers/patients). Panels may be multidisciplinary or consist of representatives from a single field.

Know-U/Fund Source of Panel Funding

The entities which provide the necessary resources for panels and organizations to conduct their activities. Examples include the federal government, industry, and professional societies through membership fees.

Know-U/Ana Compiling & Analyzing Evidence

The selection of evidence (based on a priori inclusion/exclusion criteria) and a critical appraisal of its quality (internal validity), generalizability to the U.S. primary care population (external validity), and applicability to target populations, situations, and settings). This includes consideration of the "hierarchy of research design" (RCTs, cohort studies, case-control studies, case series, case reports, ideas and opinions), methods to assess quality and strength of evidence (expert consensus [committee, Delphi review], rating scheme (GRADE), subjective review), and approaches to analysis (systematic review, meta-analysis, general review).

Know-U/Form Methods Used to Formulate Assessments & Recommendations

This involves examining and judging the cumulative evidence presented to it, and making recommendations. It include assessing the evidence at the Key Question level and across an entire Analytic Framework, assessing both the certainty of the evidence about, and the magnitude of, the harms and benefits of the service, estimating the magnitude of the net benefit for the service, and the certainty of that estimation, and finally arriving at a recommendation grade for that service in the relevant population Examples include expert consensus (Delphi, CDP, Nominal Group Technique), informal consensus, and balance sheets.

Know-U/Rec Assessments & Recommendations

These are the specific assessments and recommendations provided as panel or organizational outputs.

Know-U/Rev Review of Assessments & Recommendations

A limited number of experts and perspectives can be represented within a panel or organizational leadership; hence, development groups committed to ensuring the balance, comprehensiveness, and quality of their assessments and recommendations often share drafts with a spectrum of external reviewers expected to be evaluate the panel's evidence characterization, recommendations, etc. These reviewers may be able to challenge the logic applied by the panel in translating the evidence into recommendations; call attention to biases, political pressure, or other factors that may be coloring panelist judgments; provide suggestions for improving and clarifying messages; and allow for debate about the finding's or recommendation's rationale.

Know-U/Het Heterogeneity

Dissimilar or conflicting panel composition, processes, or outcomes.

Att Attitudes and Beliefs about Organizations and Scientific Panels

These are the evaluative and probable dimensions of panels and their outputs. Beliefs are cognitive content held to be probable and true while attitudes are reflect positive or negative feelings. Examples of attitudes include "Is the recommendation good or bad?"; "Do I support or oppose this recommendation?"; "Do I trust or mistrust this panel?" Examples of beliefs include "I think there are tensions between administrators and frontline clinicians"; "Guidelines improve quality of care."

Att-TM Trust and Mistrust of Organizations and Scientific Panels

An overall confidence and reliance (trust) or lack of confidence and suspicion (mistrust) in panels and their assessments and recommendations.

Att-TM/Cred Credibility of Composition, Processes, and Outputs

When composition, processes, and their outputs are considered worthy of trust and held in high regard specifically because of their promotion of objectivity, methodological rigor, and transparency.

Att-TM/Cred/COI Promoting Objectivity and Effective Composition While Managing Conflict of Interest

Conflict of Interest (COI) is a set of circumstances that creates a risk that professional judgment regarding a primary interest will be unduly influenced by a secondary interest. Strategies for managing potential COI and heightening objectivity "range from exclusion of conflicted members from direct participation or restriction of roles, to formal or informal consultation, to participation in certain exclusive recommendations, to simple disclosure of COI." COI, or the appearance of COI, can also occur because of funding mechanisms. Effective composition is attained when members approach the recommendation process in a manner that is objective, scientifically valid, and consistent and members create recommendations that are credible and pertinent to key affected groups.

Att-TM/Cred/Rig Methodological Rigor

The striving for excellence in research through the use of discipline, scrupulous adherence to detail, and strict accuracy. This includes compiling and analyzing data and formulating and reviewing assessments and recommendations.

Att-TM/Cred/Tran Transparency

When funding, composition, and processes are detailed explicitly and are publicly accessible.

Att-TM/Cred/Het Heterogeneity

Dissimilar or conflicting panel composition, processes, or outcomes.

Att-TM/FP Feasibility & Pertinence of Outputs

Pertinent Assessments & Recommendations

Pertinent assessments and recommendations are applicable or relevant to professional societies and their members. These outputs "should be as inclusive of appropriately defined patient populations as scientific and clinical evidence and expert judgment permit, and they should explicitly state the populations to which statements apply."

Feasible Recommendations

Feasible recommendations can be successfully implement in the context of a provider's professional practice. Examples of variables that may influence feasibility include adequacy of the health care system (e.g., availability of equipment, volume & distribution of providers; external environment (e.g., political and economic conditions; and population characteristics of both providers and patients (e.g., knowledge; beliefs; personal, family, and community resources, which include decision-support tools and other knowledge couplers for providers.

Att-TM/Care General Population vs. Unique, Individualized Care

A tension that exists when evidence for clinical decision-making is focused on a particular study population, often to the exclusion of patients with comorbidities or those from socially and economically disadvantaged backgrounds. Consequently, many recommendations "either do not address or apply to a significant number of patients."

Att-BD Benefits and Drawbacks of Outputs

Advantages and disadvantages to the volume of assessments and recommendations and their impact on professional practice and stakeholder groups (e.g., patients, researchers, payers, etc.).

Att-BD/High High Volume of Outputs and Information Overload

The rapidly expanding health literature (which grew from 5,000 published RCT per year from 1978-1985 to 25,000 per year from 1994-2001) and the difficulty professional societies and clinicians face in appraising the research and making the information "relevant to the individual patient encounter."

Att-BD/IPP Impact on Professional Practice

The effects of assessments and recommendations on professional attributes, such as expert knowledge, autonomy, satisfaction, and status, as well as the quality of care provided.

Professionals are "distinguished from ordinary rank and file workers because they are expected to exercise judgment and discretion on a routine, daily basis in the course of performing their work, i.e. discretion is a recognized and legitimate part of their work role. This characteristic, along with such others as their common training, credentials, and pay differential, is considered sufficiently distinct to justify treating them as special kinds of workers."

Att-BD/IPP/Sat Satisfaction

The degree to which assessments and recommendation affect a provider's contentment with their work.

Att-BD/IPP/Cont Professional Control

Among professions – professional control dictates who does what, under which circumstances, and for what purpose.

ATT-BD/IPP/Cont/Auto Tension between Outputs and Autonomy

A state of opposition between recommendations and the independence and authority health care providers wish to exercise in their own practice. Some question whether recommended interventions-tested under ideal circumstances with patients who met strict and narrow eligibility criteria-are relevant to certain subpopulations to certain subpopulations (e.g., patients with comorbidities and those socially and economically disadvantaged) and practice settings. Some providers complain of "cookbook medicine" (the "simplistic algorithms that fail to recognize the complexity of medical decision making and the need for individual clinical judgment").

ATT-BD/IPP/Cont/Ten Tension between Elite, Rank, and File

A state of opposition among three types of professionals "involving differences in official authority and power that in turn produce varying perspectives on the professional enterprise." For example, rank and file professionals are primarily preoccupied with "performing their work according to their own view of the intrinsic practical problems and the necessary means of coping with them on a day-to-day basis," while "supervisory professionals are accountable for the aggregate performance of workers under them and they tend to have an organizational perspective."

ATT-BD/IPP/Cont/PCvS Tension between Specialists and Primary Care Providers

A state of opposition between disease specialists and primary care providers, based on their differing education and experiences, regarding prioritization and data interpretation.

Att-BD/IPP/Qual Quality of Care

The degree of excellence in clinical practice across the care continuum.

Att-Meet Meeting Professional Society and Health Care Provider Needs for Evidence-based Outputs

The extent to which professional societies and providers have access to trustworthy, feasible, and pertinent assessments and recommendations.

Att-Meet/CFP Availability of Trustworthy, Feasible, & Pertinent Outputs

Trustworthy Assessments and Recommendations

When outputs are considered credible and held in high regard.

Pertinent Assessments & Recommendations

Pertinent assessments and recommendations are applicable or relevant to professional societies and their members. These outputs "should be as inclusive of appropriately defined patient

populations as scientific and clinical evidence and expert judgment permit, and they should explicitly state the populations to which statements apply."

Feasible Recommendations

Feasible recommendations can be successfully implement in the context of a provider's professional practice. Examples of variables that may influence feasibility include adequacy of the health care system (e.g., availability of equipment, volume & distribution of providers; external environment (e.g., political and economic conditions; and population characteristics of both providers and patients (e.g., knowledge; beliefs; personal, family, and community resources, which include decision-support tools and other knowledge couplers for providers.

PrUt Provider Utilization of Panel Outputs and Other Evidence-based Information

A provider's use or implementation of assessments and recommendations which are influenced by factors that enable or impede utilization.

PrUt-Use Use of Outputs

Whether or not a provider reports following recommendations or using evidence-based information in their practice.

PrUt-Use/Het Heterogeneity

Reactions of providers when faced with dissimilar or conflicting panel composition, processes, or outcomes.

PrUt-Fact Factors Associated with Utilization of Services

Contextual variables that influence the use of recommended health care services. These variables include the health care system, external environment, predisposing characteristics, enabling resources, need, and health behaviors.

PrUt-Fact/Sys Healthcare System

These variables involve the labor and capital dedicated to healthcare (e.g., volume and distribution of providers, equipment, and health facilities; consideration of implementation costs in decisions to provide care) and their organization, or the manner in which resources are coordinated in the process of providing care (e.g., waiting times for appointments and office waiting times in reception areas).

PrUt-Fact/EE External Environment

These variables relate to broader social, physical, political, and economic conditions, such as societal norms, national health policies, national or regional standards of care, and economic prosperity. Broad controversy regarding recommendations would be covered by this code.

PrUt-Fact/PCh Predisposing Characteristics

Predisposing Characteristics – These variables include age, education, ethnicity, gender, occupation, religion, ethnicity, and health knowledge and beliefs. For patients, these variables describe the 'propensity' of individuals to use [or not to use] services. For providers, predisposing characteristics "are intrinsic to who they are as people and how they view themselves and their roles in the system." Predisposing factors also include provider preferences and "knowledge of

and agreement with clinical guidelines and protocols and assumptions about patients and their adherence.”

PrUt-Fact/ER Enabling Resources

These reflect a patient’s means of obtaining needed healthcare using personal, family, and community resources (e.g., health insurance, income, and a regular source of care). For clinicians, enabling resources influence their capacity to provide care and include items such as reminder systems, electronic health records, and decision-support tools. Trialability- the degree to which an innovation may be experimented with on a limited basis may also be viewed as an enabling influence.

PrUt-Fact/Need Need

This involves perceived need (i.e., a patient’s self-perception of a health condition) and objective or evaluated need (i.e. a provider’s medical diagnosis, which provides external validation). Evaluated need is not simply, or even primarily, a valid and reliable measure from biological science. It also has a social component, and varies with the changing state of the art and science of medicine as well as according to the training and competency of the professional expert doing assessment. Perceived clinical impact as well as clinical guidelines and recommendations can also affect the determination of need, by setting expectations that can influence a provider’s judgment.

PrUt-Fact/HB Health Behavior

This domain refers to the direct actions taken by both patients and providers to maintain or improve health and is divided into two elements. Personal Health Behaviors – Variables in this group include patient compliance with diet, exercise, and self-care regimens and physician recommendations for screening and other services. Willingness of both patients and providers to participate in shared decision-making is another example of behavior that can affect health.

PrUt-Inf Provider Influence over Utilization Factors

A provider’s ability to have an effect on health care utilization factors

InO Innovation in Organizations

When professional societies and their members adopt ideas or practices captured within scientific panel assessments or recommendations. There is a 5-stage innovation process for organizations (i.e., agenda setting, matching, redefining/restructuring, clarifying, routinizing) and several independent variables related to organizational innovativeness (e.g., centralization, complexity, formalization, interconnectedness, size).

InO-PR Innovation Process for Organizations

The sequence of decisions, actions, and events that take place when an innovation is introduced into organization. This is not a description of strategic priorities, but may include how priorities are identified and applicable innovations are developed.

InO-Proc/Ini Initiation

"The information gathering, conceptualizing, and planning for the adoption of an innovation, leading up to the decision to adopt." Initiation includes the process of agenda setting and matching an innovation to meet the needs of an organization.

InO-PR/Ini/AS Agenda Setting

"This occurs when a general organizational problem is defined that creates a perceived need for an innovation." This stage consists of (1) identifying and prioritizing needs and problems and (2) searching for innovations to resolve needs and problems

InO-PR/Ini/Mat Matching

"Matching is defined as the stage in the innovation process at which a problem from the organization's agenda is fit with an innovation, and this match is planned and designed...At this second stage in the innovation process, conceptual matching of the problem with the innovation occurs in order to establish how well they fit. In this reality testing, the organization's members attempt to determine the feasibility of the innovation in solving the organization's problems. Such planning entails anticipating the benefits and problems that the innovation will encounter when it is implemented. The organization's decision-makers may conclude that the innovation is mismatched with the problem....terminating the innovation process prior to the new idea's implementation." Matching involves learning about the innovation (or creating it), developing attitudes & beliefs, and deciding to support or not support a recommendation, and developing policies to support it.

InO-Proc/Imp Implementation

"All of the events, actions, and decisions involved in putting an innovation into use." Implementation includes restructuring the innovation and modifying the organization's structure to create a good fit and disseminating the innovation through various communication channels.

InO-PR/Imp/Rout Routinizing/Dissemination Through Communication Channels

This "occurs when an innovation has become incorporated into the regular activities of the organization and has lost its separate identity." This also involves disseminating assessments and recommendations through various communication channels.

InO-PR/Imp/Rout/External Non-Organizational Channels of Information for Members

These communication channels are not hosted by the professional society, but do serve as sources of information for professional society members, and can include other professional society journals, newsletters, Listservs, Up-to-Date, Dynamed, the National Guideline Clearinghouse, the general media, and other sources.

InO-PR/Imp/Rout/Pref Members Preferred Channels of Communication

The communication channels (e.g., journals, newsletters, conferences, webinars) professional society members' favor when receiving information.

InO-PR/Imp/Rout/Sat Member Satisfaction with Dissemination

The degree to which members are content with the dissemination of assessments and recommendations by professional societies and other evidence-based information through other channels. This may be influenced by impressions of the organization's trustworthiness or pertinence. This code may include coverage of specific topics which are satisfying or unsatisfying to members.

InO-Char Organizational Background & Characteristics

This provides information on the organizational setting (e.g., history, mission) as well as independent variables related to innovativeness (e.g., centralization, complexity, formalization, interconnectedness, organizational slack, size).

InO-Ch/Over Overview/History/Mission

Background information on the history of the organization and a general overview of the professional society and its mission, goals, priorities, and programs.

InO-Ch/Cent Centralization

The degree to which power and control in a system are concentrated in the hands of a relatively few individuals and the structure that permits decision-making and governance.

InO-Ch/Comp Complexity

The degree to which an organization's members possess a relatively high level of knowledge and expertise, usually measured by the member's range of occupational specialties and their degree of professionalism (expressed by formal training).

InO-Ch/Formal Formalization

The degree to which an organization emphasizes its members' following rules and procedures.

InO-Ch/Inter Interconnectedness

The degree to which units in a social system are linked by interpersonal networks.

InO-Ch/Size Size

The number of members and staff in a professional society.

InO-RIn Perceived Relative Innovativeness

The degree to which individuals view themselves or their professional society as adopting new ideas earlier than others in the system.

Value Value Federal Government Contributes to Evidence-based Practice by Developing & Disseminating Assessments & Recommendations

The distinct benefit contributed to evidence-based practice by federal scientific panels.

Value-Tran Transparency

When panel funding, composition, and processes are detailed explicitly and are publicly accessible.

Value-Obj Objectivity

When panel member decisions and panel processes are based on a primary interest and not influenced by secondary financial or intellectual concerns.

Value-Rig Methodological Rigor

The striving for excellence in research through the use of discipline, scrupulous adherence to detail, and strict accuracy.

Sugg Suggestions for Federally-Sponsored Panels to Consider for the Development of More Trustworthy, Feasible, & Pertinent Outputs

Ideas for the NIH to consider to strengthen panel composition and processes so that assessments and recommendations can be more trustworthy, pertinent, and feasible.

Sugg-TW Trustworthy Assessments & Recommendations

When outputs are considered credible and held in high regard.

Sugg-Pert Pertinent Assessments & Recommendations

Pertinent assessments and recommendations are applicable or relevant to professional societies and their members. These outputs "should be as inclusive of appropriately defined patient populations as scientific and clinical evidence and expert judgment permit, and they should explicitly state the populations to which statements apply."

Sugg-Feas Feasible Recommendations

Feasible recommendations can be successfully implement in the context of a provider's professional practice. Examples of variables that may influence feasibility include adequacy of the health care system (e.g., availability of equipment, volume & distribution of providers; external environment (e.g., political and economic conditions; and population characteristics of both providers and patients (e.g., knowledge; beliefs; personal, family, and community resources, which include decision-support tools and other knowledge couplers for providers.

Feed Feedback on Study

Comments regarding the study itself, including aims, questions, recruitment, interviews, etc.

Appendix 17: NIH Office of Human Subjects Research Response to Request for Review

OHSR RESPONSE TO REQUEST FOR REVIEW OF RESEARCH ACTIVITY INVOLVING HUMAN SUBJECTS

FAX:

Exempt #: 11735

To: Neilson, Elizabeth
OD
6100 EXECUTIVE BLVD RM 2B03

From: Office of Human Subjects Research (OHSR)

Nature of Research Activity:

A total of 30 people (leaders and members of eight professional societies) will be interviewed to learn how health providers and their organizations view and act on evidence-based recommendations. The information gained will enable the NIH Consensus Development Program to better design and communicate its recommendations to these stakeholders.

Original Request Received in OHSR on: 12/20/2012

Responsible NIH Research Investigator(s): Elizabeth Neilson, OD

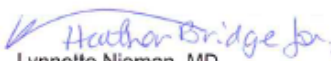
OHSR review of your request dated Mon, Dec 17, 2012 has determined that:

- ☐ Federal regulations for the protection of human subjects do not apply to above named activity. The OHSR determination of Not Human Subjects Research is based on the interpretation of 45 CFR 46 under "Research Involving Coded Private Information or Biological Specimens" (OHRP, Revised October 16, 2008) and Guidance on Engagement of Institutions in Human Subjects Research (October 16, 2008). NOTIFY OHSR VIA AN E-MAIL AMENDMENT OF ANY CHANGES THAT MAY ALTER THIS RESEARCH ACTIVITY.
- ☒ The activity is designated **EXEMPT**, and has been entered in the OHSR database. PLEASE NOTIFY OHSR OF ANY SIGNIFICANT CHANGES THAT MAY ALTER THE EXEMPT STATUS OF THIS RESEARCH ACTIVITY.
- ☐ **NOT EXEMPT.** OHSR recommends IRB review. Please forward your request to the Chair of your IRB, who may ask you to provide additional information in order to determine whether expedited or full review is appropriate.
- ☐ Confidentiality Agreement
- ☐ Reliance
- ☐ Amendment
- ☐ Other

Note:

Office Person HB

Admin Assist. CB


Lynnette Nieman, MD

Director, OHSRP

1/17/2013

Signature

Title

Date

Domestic/International:

Domestic

Human Subjects Data: Yes

Biologic Material: No

OHSR Use Only

☐ 1 ☒ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6

Appendix 18: Acronyms

AACR	American Association for Cancer Research
AAFP	American Academy of Family Physicians
AANP	American Association of Nurse Practitioners
AAP	American Academy of Pediatrics
AAPA	American Academy of Physician Assistants
ACA	Affordable Care Act
ACG	American College of Gastroenterology
ACIP	Advisory Committee on Immunization Practices
ACOG	American College of Obstetricians and Gynecologists
ACP	American College of Physicians
ACR	American College of Radiology
ACS	American Cancer Society
AGA	American Gastroenterological Association
AHRQ	Agency for Healthcare Research and Quality
AMA	American Medical Association
AMWA	American Medical Women's Association
AOA	American Osteopathic Association
ASGE	American Society for Gastrointestinal Endoscopy
CAT	Computerized axial tomography
CDC	Centers for Disease Control and Prevention
CDP	Consensus Development Program
CHR	Committee on Human Research
CIPP	Context-Input-Process-Products
CME	Continuing medical education

CMSS	Council of Medical Specialty Societies
COPD	Chronic obstructive pulmonary disease
CRC	Colorectal cancer
CRS	Congressional Research Office
CT	Computed tomography
CTC	Computed tomographic colonography
DCBE	Double contrast barium enema
DNA	Deoxyribonucleic acid
DO	Doctor of Osteopathic Medicine
DRE	Digital rectal exam
EHR	Electronic health record
FBOT	Fecal occult blood test
FDA	U.S. Food and Drug Administration
FIT	Fecal immunochemical test
FS	Flexible sigmoidoscopy
GAO	Government Accountability Office
gFBOT	Guaiac-based fecal occult blood test
GIN	Guidelines International Network
GRADE	Grading of Recommendations Assessment, Development and Evaluation
HMO	Health maintenance organization
HRSA	Health Resources and Services Administration
IOM	Institute of Medicine
JNC	Joint National Committee on Prevention, Detection, and Treatment of High Blood Pressure
LSU	Louisiana State University
MRI	Magnetic resonance imaging

MSTF	U.S. Multi-Society Task Force
NAS	National Academy of Sciences
NCI	National Cancer Institute
NGC	National Guideline Clearinghouse
NHLBI	National Heart, Lung, and Blood Institute
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIH	National Institutes of Health
NP	Nurse Practitioner
ODP	Office of Disease Prevention
OHSR	Office of Human Subjects Research
ONC-NLC	Office of the National Coordinator for Health Information Technology and National Learning Consortium
OTA	Congressional Office of Technology Assessment
P2P	Pathways to Prevention program
PA	Physician Assistant
PSA	Prostate specific antigen
QALY	Quality adjusted life years
RCT	Randomized controlled trial
UCS	Union of Concerned Scientists
USPSTF	U.S. Preventive Services Task Force

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CURRICULUM VITAE

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EDUCATION

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| 2014 | Doctor of Philosophy in Social and Behavioral Sciences, Johns Hopkins University School of Public Health, Baltimore, MD. |
| 2000 | Master of Public Health and Master of Science in Community Health Nursing, Johns Hopkins University, Baltimore, MD. |
| 1995 | Bachelor of Science in Nursing, Emory University, Atlanta, GA. |

PROFESSIONAL EXPERIENCE

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|----------------|--|
| 2010 – Present | Senior Advisor , Office of Disease Prevention, National Institutes of Health (NIH), Bethesda, MD. Conducts strategic planning, implementation, and evaluation of communication activities. Coordinates media relations and serves as liaison between NIH staff and print, electronic, and broadcast journalists. Oversees the development and distribution of educational materials for a variety of internal and external audiences. Oversees all aspects of the Office of Disease Prevention website. |
| 2004 – 2010 | Advocacy Relations Manager , National Cancer Institute (NCI), Bethesda, MD. Served as liaison between consumer advocates and the NCI scientific community. Conducted strategic planning, data analysis, training, evaluation, and program promotion. Served as advocacy subject matter expert for NCI staff, and primary point of contact regarding breast and gynecologic cancer research for the advocacy community. Member of NCI's Clinical Proteomic Technologies for Cancer (CPTC) leadership team. Member of a national steering committee and state advisory board focused on increasing cancer screening through evidence-based strategies. Served on special projects for the Breast Health Global Initiative and the Fogarty International Center, Office of Communications. |
| 2001 – 2004 | Program Director , District of Columbia Department of Health, Washington, DC. Directed all components of the Breast and Cervical Cancer Early Detection Program. Developed and monitored program budget, contractual agreements, and strategic plans. Prepared grant applications, surveillance reports, and data submissions. Built collaborative relationships with health providers, community-based organizations, and government agencies. Organized public education and |

outreach activities. Ensured quality assurance of clinical and case management services. Supervised and provided leadership to staff.

- 2000 **Area Manager / Registered Nurse**, Planned Parenthood of the Columbia Willamette, Portland, OR. Managed staff, operations, and budget of area clinic. Developed initiatives to increase client satisfaction and operational efficiency. Provided education, public advocacy, and clinical services to promote access to comprehensive reproductive and complementary healthcare.
- 1996 – 1998 **Public Health Nurse**, Fulton County Health Department (FCHD), Atlanta, GA. Assessed and taught clients preventive health and health promotion practices. Provided communicable disease control, pregnancy-related services, and cancer screening to diverse communities. Acted as liaison between FCHD and community representatives and agencies.
- 1995 – 1996 **Registered Nurse**, Crawford Long Hospital, Atlanta, GA. Ensured quality, holistic patient care on a medical/diagnostic/telemetry unit.
- 1990 – 1991 **Staff Member**, Volunteers in Service to America, Atlanta, GA. Assisted with the resettlement of refugees. Created and implemented culturally sensitive health programs concerning cancer prevention and control, child health, reproductive health, and communicable disease control.

TRAINING

- 2013 NIH, Plain Language Training
- 2012 NIH, Protecting Human Research Participants Training
- 2012 University of Colorado School of Public Health, Rocky Mountain Workshop on How to Practice Evidence-Based Health Care
- 2011 NIH, Medicine in the Media Course
- 2009 NIH, Introduction to Global Health Course

PUBLICATIONS

Yabroff KR, Washington KS, Leader A, **Neilson E**, Mandelblatt J. (2003). Is the promise of cancer-screening programs being compromised? Quality of follow-up care after abnormal screening results. *Medical Care Research and Review*, 60(3):294-331.

HONORS AND AWARDS

- 2012 National Institutes of Health, Office of the Director Honor Award

2007	Johns Hopkins University School of Public Health, Department of Health, Behavior and Society Full-Tuition Scholarship
1995	Emory University Associates' Silver Bowl Award to the Most Outstanding Senior (chosen by the faculty)
1995	Emory University Embodiment of Nursing Award (chosen by the student body)
1995	Sigma Theta Tau Honor Society
1993	Emory University Woodruff Scholar